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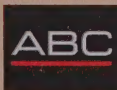
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# editorial

## Loose language costs lives ✓

There are some subjects to which *Disability Now* regularly and frequently returns. And we make no apology for doing so.

One such is disability hate crime – disabled people being targeted for verbal and physical abuse, robbed, tortured, terrorised, harassed and killed because of what we are.

We've previously highlighted the avoidance by politicians, police, judges, even those in the disability sector of talking about hate crime as what it is. In the past they've talked about "vulnerability", as if what we are should make us expect to have violent and criminal treatment meted out to us. This is equivalent to those people who used to say that women being in a particular part of town after dark were effectively asking to be raped.

Nothing can justify violation of a person because of what they are. Such acts are always and only the responsibility of the perpetrator.

Hate crime has also been trivialised by organisations which purport to represent disabled communities.

Following the harassment to death of Fiona Pilkington and her family, for example, Mencap spokespeople talked in terms of "this kind of bullying" being unacceptable.

These were not people who were bullied. They were targeted specifically because some of them were disabled.

Since the Pilkington tragedy and following the death of David Askew, the emphasis has shifted again. In both cases, the victims (not a word we ever use lightly) have been described as being subject to "anti-social behaviour".

Once again, behaviour which routinely and systematically targets disabled people for harassment, abuse, violence and worse goes beyond being anti-social.

What's worse is that this type of obfuscation, when hate crime is not described as hate crime, means that it will probably not be investigated as hate crime and may therefore never reach the criminal justice system where it should ultimately be prosecuted as hate crime and punished as hate crime.



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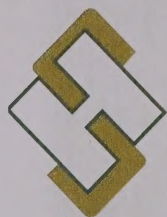
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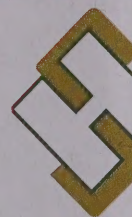


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# Sussex Health Care



Sussex Health Care is an award winning group of care homes that were founded in 1985. Sussex Health Care now operates 16 care homes, predominantly in the West Sussex area, providing nearly 550 beds, incorporating specialist care provision including care for older people.

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# Flood launches manifesto for inclusion

Ian Macrae

The Alliance for Inclusive Education (ALLFIE) has set out a series of demands for a more fully inclusive education system.

The campaigning group has produced a manifesto which lists six prerequisite requirements for making mainstream learning available to all disabled people.

Among these are a legal right to inclusive education, all educational premises to be fully accessible, a fully inclusive and accessible mainstream curriculum and more inclusive and accessible assessment and accreditation procedures for qualifications.

ALLFIE's Chief Executive Tara Flood (pictured) has told *Disability Now*: "For years inclusive education has been a real political football. This is something for people to take along and show to their prospective parliamentary candidate and say, 'This is what I believe in and what you should act on'."

ALLFIE believes that the predominant views of politicians are skewed against inclusion because they hear disproportionately from people who are against it.

"The parties are aware of



JAMIE TROUNCE

the voices of a minority of parents whose children have been failed by mainstream. But overcoming those failures is about getting learners the right level of support and schools being more welcoming and demolishing the barriers created by local authorities. Many parents don't have the energy for that sort of battle or the resources for taking on schools or local authorities to get their disabled child into mainstream. So they

feel they have no choice but to go down the special school route", says Flood.

This creates among politicians the erroneous notion that, given the option, parents would more often choose special school provision over a place in their neighbourhood mainstream school.

A combination of mindset in the system and a certain amount of vested interest also militate in favour of accepted wisdom that special schools

are where disabled children belong.

"The minute you are identified as having Special Educational Needs (SEN), you fall out of automatic entitlement to a mainstream place. There's also been a concerted effort by the special school lobby who have a great deal to lose from full inclusion. They exploit parents who are in a vulnerable position, who in fact have a very difficult time because the system is set up to fail them and their children."

Does the fact that the leaders of both main political parties have experience as parents of disabled children make her hopeful that they will each have a more informed approach to inclusion? Flood is reluctant to talk in personal terms about either David Cameron or Gordon Brown, but she does identify a difference between them.

"Cameron's mistake when it comes to policy decisions is that they're very much driven by personal experience. The respect I have for Gordon Brown is that he's kept his children out of the political limelight. He also has a better sense of social justice."



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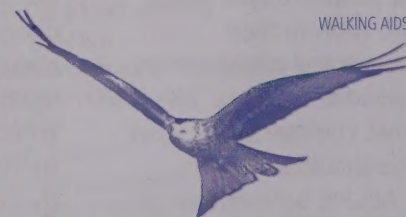
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# newsupdate

## New assessment threatens benefits



**Cathy Reay**

Campaigners for disability rights are protesting that planned changes to the Work Capability Assessment (WCA) will force thousands of disabled people into poverty.

Welfare rights activists have hit out at the Department for Work and Pensions' (DWP) planned revisions to the WCA, claiming that the new rules will cut off benefits for

thousands of disabled people.

In a new paper, "Building Bridges to Work", the DWP has proposed that benefits claimants are reassessed so that many can be taken off "inactive benefits" and then that they are subsequently put on "more appropriate benefits that provide greater employment support".

Steve Donnison, disability and welfare rights campaigner and author of a

benefits and work blog ([benefitsandwork.co.uk](http://benefitsandwork.co.uk)) said: "This is barbaric. The DWP is attempting to push thousands of people onto Jobseekers Allowance, even though the Government is aware a lot of those people may never be employed. This is nothing but an ugly way to save money."

Jaspal Dhani (pictured), chief executive of the United Kingdom's Disabled People's Council (UKDPC), said that the situation "suggests yet another Government initiative to get people off Incapacity Benefit."

He added: "This system of assessments is likely to push disabled people into greater poverty. Jobseekers Allowance won't cover living costs."

The Department has said that the WCA will ensure that appropriate account is taken of an individual's adaptation to their condition or disability. However, Neil Coyle, policy director at Disability Alliance, said that the system still needs to be more personalised.

"The WCA is not flexible enough to reflect the needs of disabled people. An independent analysis is required to prevent the wrong assessments from

being issued, which will put people on the wrong benefits at a lower rate than they should receive and cause a cost to restricted public resources through expensive appeals."

The paper also advises that the Government should work in partnership with employers to ensure that "no-one is written off", though it does not state how they plan to tackle discrimination at work.

UKDPC's Jaspal Dhani said that the DWP needs to do more to encourage employers to give jobs to disabled applicants.

"It seems as though they are blaming disabled people for being unemployed rather than addressing the problem with employers; one and a half million disabled people in the UK are willing and able to work but can't get jobs, shouldn't they be asking why?"

A spokesman for the DWP said that DWP is committed to an Independent Review of the Work Capability Assessment every year for the first five years of operation.

The independent review is currently being commissioned and will report its first findings later in 2010.



# newsupdate

## Anger as ILF changes threaten independent living

Sunil Peck

The Independent Living Fund's (ILF's) decision to restrict new applications for financial support to disabled people who work more than 16 hours a week undermines the Government's commitment to advancing equality, campaigners claim.

The ILF is funded by the Department for Work and Pensions (DWP) and at present provides money for claimants between 16 and 65 with high support needs regardless of whether or not they work and who receive local authority support worth more than £320 a week.

But changes are being introduced that mean that from May 1, the ILF will only accept new applications from people who are in paid work for more than 16 hours a week.

Jim Elder-Woodward, Convenor of the user-led project Independent Living in Scotland, accepts that cuts are inevitable in the current economic climate. But he says that the changes will bring about a contradiction that could have been avoided if

disabled people had been consulted about changes.

He said: "Local authorities are prioritising very severely disabled people who have no real chance of getting a job because of the extent of their impairment. But the ILF are only interested in supporting those people who can work for more than 16 hours a week."

Rachel Hurst, Director of

Disability Awareness in Action, said that the fact that the ILF was making changes without consulting disabled people showed that despite its rhetoric, the Government was not interested in co-production or personalisation for disabled people.

She said: "I am angry, frustrated and sad that disabled people are the butt of cost-cutting exercises

from Government."

In 2007 an independent review criticised the ILF for a lack of user involvement and lack of accountability and transparency in the ways it made decisions.

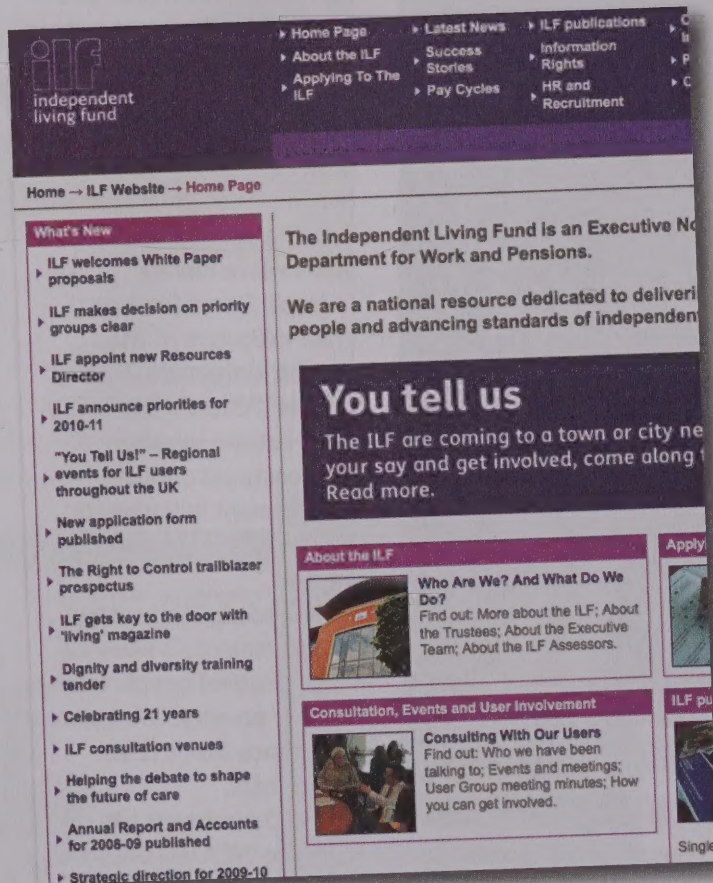
Commenting on the new changes to eligibility criteria, Sue Bott, Director of the National Centre for Independent Living, said: "I'm really very angry about this. This completely goes against the review of the ILF which the Government seems to have shoved aside because it raises too many difficult questions."

She warned that the changes would be "devastating for disabled people".

A spokesman for the ILF told *Disability Now* that the decision to restrict eligibility for new applicants had been prompted by the rising costs of existing users' care packages.

He said that existing claimants were the ILF's first priority and that they would not be affected even if they did not meet the employment requirements for new applicants.

The ILF is also increasing the threshold sum that local authorities are required to meet in order to access ILF funding, and for increases to existing users care packages, from £320 to £340 a week.





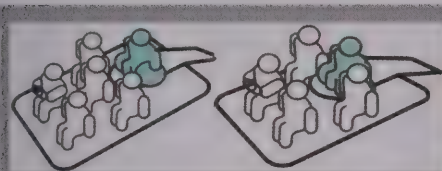
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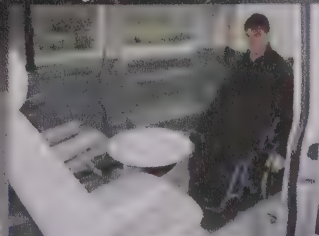
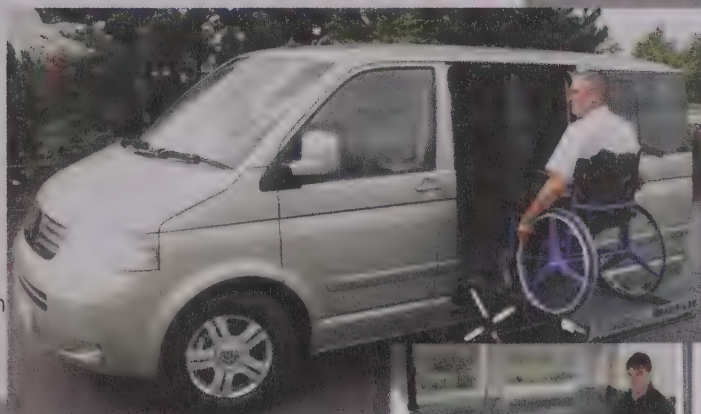
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## Fitness regime: a question of balance



The Government's recently introduced fit note represents more than just a change of emphasis, and could, says **Ruth Patrick**, signal a real power shift between GP and patient

**A**s of April 2010, people going to their doctor to be signed off as too ill to work will no longer receive the traditional sick note. The Government has introduced changes which replace sick notes with fit notes. Under the new regime, a doctor can either determine that a patient is entirely fit to work and thus refuse to sign the fit note, or sign them off as "not fit to work". So far, so familiar, but now, GPs have a third option: they can assess a patient as someone who "may be fit for work" if their employer takes account of advice which is incorporated within the fit note. Thus, a GP might recommend a phased return to work, altered working hours, amended duties or the provision of workplace adaptations.

The focus on capability rather than deficit is to be welcomed, as is the introduction of a more personalised regime which includes greater subtlety than the old can/can't work choice previously available to doctors.



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**It is the patient who is the expert on their own condition and related requirements and not their doctor. By placing the power with the GP, this reform disempowers the individual patient**

But the idea that an effective assessment of a patient's individual needs can be made by a GP, particularly given the

limitations of a ten minute consultation, is dubious. It is the patient who is the expert on their own condition and related requirements and not their doctor. By placing the power with the GP, this reform disempowers the individual patient and prevents them from taking a more active role in their own recovery and return to work.

Ironically, doctors' recommendations are not binding and the employer has no legal duty to implement their suggested changes to enable someone

who "may be fit for work" to re-enter the workplace. This weakens the potential in the reforms and also creates murky water as to the "fitness" status of an employee declared possibly fit to work, when the employer refuses to follow the doctor's advice.

What is more, fit notes are part of the Government's wider work-first approach, which conceptualises paid work as the central route to well-being, contentment and citizenship. This approach risks alienating and excluding all those who cannot work or who choose instead to engage in other equally valuable activities such as unpaid work, caring and parenting. The Government rhetoric behind the fit note reform is suggestive of further steps to put an end to a so-called sick-note culture, and the tabloid press has welcomed their introduction as an important effort in the fight to separate the genuinely sick from the benefit-addicted work-shy. Such spin, which trades on plenty of supposition and very few facts, does disabled people absolutely no favours.

The conclusion is clear. Despite some positive aspects, the new fit notes are simply not fit for purpose.




# politics

## Election 2010: They want your vote

In the run-up to the General Election each of the five main political parties has told *Disability Now* why we, as disabled people, should vote for them

### Conservative Party

 Conservatives believe that to have a disability should not be a barrier to anyone fulfilling their aspirations. But disabled people today still face unacceptable barriers in many areas of their lives which hold them back from living independently.

It is our job to break down these barriers and ensure that disabled people have the same chance to succeed and to fully participate in our society. That is why the Conservative Party is committed to making the

changes to our welfare system so that disabled people who are out of work but able to work get the proper help and support to move into employment.

We want to see a more personalised social care system so that disabled people can take charge of their own lives and design their own services according to their needs.

We will simplify the benefit system to ensure that it provides better support to those who need it most, and helps people to move into work, rather than being forced to stay on benefits.

### Green Party



The Green Party would rather tax the rich much more to cut their excess wealth and pay back national debt than cut the benefits and care services for those too disabled or sick to work.

We would spend public money on making a million "green jobs", for example: preparing empty homes for people to live in them; insulating poor people's homes to cut their fuel bills; building more trains, trams and buses, and making

public transport more accessible; and growing more food.

We would also introduce citizens' pensions at £170 a week and carers' core income at £80 a week; work towards introducing non-means-tested citizens' income; repeal the Welfare Reform Act 2009; stop the creeping privatisation of the NHS and other vital services; end student tuition fees; withdraw from Afghanistan; scrap ID cards scheme; take firmer action against disability hate crime; and promote equality training for all public sector workers.

### Labour Party



Labour is determined that the UK should always be a world leader in disability rights and we have legislated to provide protection against discrimination at work, while also offering new support for people into work.

We will always seek to strengthen the rights of disabled people to access services, work and be supported to make the choices they want to make in their own lives.

Our measures include bringing forward part of next year's increase to be able to raise Disability Living Allowance above


inflation this year; and from April 2011 we will extend the higher rate mobility component of DLA to over 20,000 severely visually impaired people.

We are introducing "The Right to Control", a legislative right for disabled people to give them greater choice and control over some of the funding they receive from the state. And from April 2010, there will be additional annual payments of £100 into the Child Trust Fund accounts of disabled children.

Severely disabled children will receive £200 per year. We are further strengthening disability discrimination legislation through the Equality Act.



## Liberal Democrats

 For the Liberal Democrats this election is about one thing: fairness. In a fair Britain, a person will never have to do without the basics – like heating they can afford, or public transport they can rely on – because of their disabilities. We'll extend the Winter Fuel Payment so up to one million people with severe disabilities get an extra £250 towards their bills, and we'll put thousands of new, accessible buses on

our roads through a bus scrappage scheme.

In a fair Britain, we'll make sure children with disabilities get more support at school and adults with disabilities get more practical help at work. We'll reform the Access to Work scheme to allow jobseekers to apply for the grant while they are looking for a job. We'll integrate health and social care so they work better. And we'll get politics out of the debate on social care so we can find the answer to Britain's social care needs.

## UK Independence



UKIP, the United Kingdom Independence Party, seeks the fulfilment of individual potential, regardless of background or circumstances.

For those of school age, UKIP will ensure that education is tailored to the needs of each pupil, with tests used to assess both academic and vocational aptitudes.

The party will also re-examine the way disabled pupils are integrated into

often inappropriate schools and do all it can to promote and support special schools for children who have disabilities.

On the benefits front, UKIP will act to safeguard the disability living allowance, the attendance allowance and the mobility allowance.

And regarding taxes, the Party will scrap all tax on earnings below £11,500, so that people find themselves in a position to take temporary work without their being penalized financially.



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# mediawatch



## Wheels come off Beeb *Strictly* spin-off

It is as if their view was, 'They're not worth it so we can treat them like \*\*\*\*.' It's clear discrimination."

Those were the damning words of 31-year-old James O'Shea, a wheelchair-user from Hertfordshire who beat six other disabled contestants to win BBC3's *Strictly Come Dancing* spin-off earlier this year.

The show, which paired previously inexperienced disabled wheelchair dancers with celebrity partners and which had been heavily hyped by the BBC prior to broadcasting in March, was lauded as a cutting-edge talent programme that would increase awareness of wheelchair dancing as a serious sport. A prize of representing the UK in the European Wheelchair Dance Sport Championships in Tel Aviv was awarded to James and his dancing partner, TV presenter and former *Strictly* dancer, Caroline Flack.

But his win didn't pacify the reality TV star. Speaking to the *Mail on Sunday* (MoS) in the only interview the dancer has granted since the contest ended, James reveals that a member of the crew discriminated against him during filming. He says that a cameraman threatened: [I'm going to] "tape your arms together, throw you into the Thames so only your nose is just above the water and then push you down every

He may have won the show but he's not dancing with delight. BBC3's *Dancing on Wheels* champion James O'Shea has hit the headlines claiming that the programme's makers discriminated against its disabled contestants. **Cathy Reay** tries to get to the truth behind his allegations



couple of minutes until you've learned your lesson".

James also alleges that the BBC and Fever Media, the independent production company commissioned to make the series, discriminated against the contestants by offering them less money than their celebrity dance partners. O'Shea claims that he had originally been offered £450 a week to appear on the show, but was actually given less than half of that.

He told the MoS, "I asked the producers if they could look at anyone and tell them they're only worth

**I'm going to tape your arms together, throw you into the Thames so only your nose is just above the water and then push you down every couple of minutes**

£150 a week. I told them that I wanted at least double that amount for all the competitors. It makes no sense. They're trying to make a TV show [that makes] a good portrayal of

disabled people, yet they're not going to pay them."

Harry Lansdown, the BBC's Commissioning Editor for Factual Entertainment who commissioned *Dancing on Wheels*, said that James' comments disappointed him. Speaking to *Disability Now*, he argued: "Comments made by the cameraman were not correctly reported. James received an apology from the cameraman who realised that, even in jest, his comments could be seen as upsetting or unprofessional.

"With regards to pay for the contributors, we strongly

reject any suggestion that we treated the contestants in this show differently to those in any other factual entertainment programme. Neither James O'Shea nor any other of the wheelchair-users were ever offered £450 a week to appear in the show."

Following our request for interviews with others of the show's disabled contestants, the BBC said that they'd decided not to make them available for comment at the time of going to press. BBC3 currently has no plans to commission a further series of *Dancing on Wheels*.



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# disabilityrights

## White Paper is whitewash

**T**he outgoing Westminster Government's White Paper on social care proposes introducing a National Social Care Scheme in England and Wales, on a universal and comprehensive scale – a plan of which William Beveridge, the father of the National Health Service, would be proud.

There'll be no more post-code lotteries, and no more extortion by local authority charging policies.

The White Paper states that the scheme will:

- Support all adults with care and support needs within a framework of national entitlements
- Be free at the point of use
- Be based on need, rather than the ability to pay
- Ensure choice and control
- Treat everyone with respect and dignity; putting people in charge of their lives.

But wait for it; don't crack open the champagne yet! There are several hurdles still to overcome. To name but a few, the measure relies on Labour's winning the next general election; a consensus being achieved over funding; yet another commission being set up (remember the one Tony Blair launched in 1997?);



Following the publication of the current Government's White Paper on social care in the last few weeks, **Jim Elder-Woodward** blasts a few myths and highlights some realities about differences north and south of the border



and legislation being brought in piecemeal over the next six years. That's right, six years, if not longer!

In the meantime, disabled adults will still be at the mercy of their local authority's pick-and-mix of services, threatening: "Give us your money, or we'll take away your right to live independently and be an equal citizen!"

English commentators in the media often say that there's free personal care in Scotland. There isn't, and it makes my blood boil when I hear it said!

In 2008-2009, adult care charges brought in z to the exchequers of local authorities. That's slightly more than the £310m it is now costing the Scottish Government to pay for the

freeze on council charges.

It's difficult to understand how politicians can justify why someone with no need for education has to pay for someone else's educational needs but someone without any social care needs shouldn't have to pay for someone else's social care needs.

Disabled people are also asking the Scottish Government in its 2011-2014 spending review to ponder why it should be proper to charge disabled adults to exercise their rights to independent living and full and equal citizenship, but improper to charge for art and museum venues; and why it's proper to give everyone, irrespective of income, but aged over 60, free nationwide bus travel, but improper to give subsidised taxi fares to those who can't get on a bus.

North and south of the border, there really needs to be a public debate over taxation and public service charges.

I suppose the one thing we should all be grateful for, north and south of the border, is that social care, and in particular self-directed support or its equivalent, is beginning to be discussed on a par with health and education by both national and local politicians.





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**Ian Williams** living with MS

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# worldview



## Bolivia: a high mountain to climb

**Feliza Ali Ramos** (seen seated, opposite) is the disability programme co-ordinator with the Bolivian field team of development agency International Service. She reflects on her own life as a disabled woman in Bolivia and discusses how she is working to support people with disabilities in the fight for equal rights

**O**n 23 September 1997, my life changed forever when the driver of the bus I was going home on fell asleep at the wheel. We plunged 70 metres down a hillside and five of the 12 passengers died. I received fractures to my spine and right knee. Since the crash I haven't had any sensation in my legs. I've had six

operations, in one of which doctors removed my right patella without permission.

Later, I found that two events had acted against my full recovery. Foreign doctors who happened to be travelling as tourists on the bus had picked me up face-down and warned I shouldn't be turned over, due to spinal injuries, but the radiologists at the

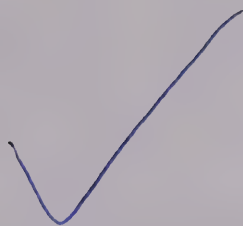
hospital seemed unaware of this and put me on my back, resulting in further disfiguration of the fractured vertebrae pressing down on the spinal cord.

In addition, because I was single, I needed authorisation for surgery which meant my parents had to come to the city of Potosi (where I was in hospital), delaying surgery until 48 hours after

the crash. This was fatal because damaged brain cells related to the spinal cord die after about six hours and never regenerate. If I'd received surgery sooner, further damage could have been prevented.

My first years in a wheelchair meant a constant fight for acceptance. I felt strongly the difference in how people with and without disabilities





were treated. People think we have to have decisions taken for us, and we often have no chance to object. So I started to challenge this.

I did an analysis and found that disabled people in Bolivia are discriminated against. Public spaces or buildings are inaccessible; so are public toilets. I often wonder who can work for a day without going to the toilet. I think it's inhumane.

Then there's the social barrier: people's reactions to disability. People think wheelchair-users are good for nothing or that we're ill. I have a degree in social work and looked for a job in that area but colleagues thought I couldn't manage, so I stopped looking.

People said my disability was a punishment from God. I asked forgiveness for my sins for more than four years but then realised that having a disability is neither a blessing or misfortune. It's simply something that gives you a different perspective, allowing you to value human qualities differently.

I started to gather my disabled comrades and to suggest we organise ourselves. I formed the New Hope association of people with disabilities, then the Federation of Persons with Disabilities in Chuquisaca, and later the state-funded Committee of Persons with Disabilities in Chuquisaca.

Bolivia doesn't have official statistics on disabled people so we use figures from the World Health Organisation. These state that ten per cent of the population in developing countries has a disability, which works out at over 827,000 Bolivians. In addition, 62 per cent of our disabled population is poor; 39 per cent are classified as destitute; and 97 per cent get no education. That gives us almost no chance of individual development.

I joined International Service, a UK-based international development agency, as co-ordinator of its disability programme in Bolivia. We joined forces with disabled people's organisations and other NGOs and managed to get disabled people's rights recognised as part of the constitution. In January 2009 a new constitution was adopted that recognised disabled people's right to education, free healthcare, good working conditions and the right to develop individual potential. The state now prohibits and punishes all forms of abuse, discrimination, exploitation and violence, and ensures access to prevention and rehabilitation services.

We've also worked to support the creation of job opportunities, the establishment of a national plan for

equal opportunities, the development of a national register of people with disabilities, the recognition of sign language, and the reclassification of blind teachers so they can receive their due benefits.

The two main disabled people's organisations in Bolivia are the National Federation of Blind People and the Confederation of People with Disabilities. These bodies have made progress in promoting our rights but there has been interference from different political parties and their ideologies have divided us, diverting us from our main mission. While they've put disability on the central government agenda, the movement as a whole has been weakened.

The Government has 40 million Bolivianos (approximately £4m) to spend on projects for people with disabilities. This is a huge step forward. However, the professionals implementing these programmes don't know about disability issues. They carry out activities from a medical rather than a social perspective, seeing disabled people always as objects in need of charity.

We're convinced this is not the way to address the issue. We want social

inclusion and this will only happen when society accepts and takes account of us in all the economic and social developments of our beloved Bolivia. We want our international motto to be fulfilled and translated into law: nothing for us without us.

Our strategy up to 2015 is to strengthen the dialogue between the grass roots disability organisations and the Government. Then we can ensure that national development programmes are truly inclusive.

Living in Bolivia with a disability is a constant struggle but I love my country and want to do my part in moving it forwards.





# onetowatch



## Pulling power

Having lost most of his sight and lower limb strength after a brain haemorrhage in 2007, **Scott Ballard-Ridley** became even more determined to achieve his dream of being a professional rower. After winning a Disabled Sports Personality of the Year Award, and *en route* to competing in the 2012 Paralympics, he tells us about his passions

### What's the best thing about being disabled?

A wider appreciation of what it's like to have a disability and of things I took for granted before.

### What's the funniest thing anyone has ever said to you about your impairment?

When I won the Disabled Sports Personality of the Year Award at the

Hereford and Worcester Sports Awards recently, the photographer took a picture of me and then said "Sorry about the flash, I didn't mean to blind you". I told him not to worry about it; I'd beaten him to it!

### What makes you angry?

Some people with visual impairments can be very closed-minded when it comes to trying new things.

And of course when rowing, losing makes me angry!

### If you were Prime Minister, what would you do to improve things for disabled people?

I'd improve standards in accessibility, such as wheelchair access to shops, as well as awareness of visual impairment and other disabilities.

### What could be invented to make your life as a disabled person better?

It's already been invented: access to books, magazines and other written materials with e-books and the new iPad. These things will revolutionise reading for me and many others.

### What do you like most about rowing?

I love the feeling you get after a hard training session and the team aspect and inclusivity of being in a rowing club. For me, Evesham Rowing Club has supplied me with everything I've wanted to do; I really owe them a lot.

### What do you like least about rowing?

The early mornings are tough – 5am starts when I'm training. Being out on the water at that time when it's cold is horrible.

### Who's your favourite disabled person ever?

People with disabilities often have a negative outlook on life and they've inspired me *not* to be like them! By contrast, my good friend Arthur Williams, who was in the Marines until he suffered a spinal injury, is on his way to the Paralympics as a wheelchair-racer. His gung-ho attitude is something I really admire.

### Do you have any special or hidden talents?

As an ex-rugby player, I can down a pint in under four seconds.

### Can you sum yourself up in ten words or less?

I always try to turn perceived disadvantages into advantages.

### → Who do you think is One to Watch?

Send us your nominations for likely lads and lasses who could answer our 10 questions. They can be rising stars in any field of entertainment, business, the media or beyond

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# Genevieve raises the Barr



Despite landing her first big part purely by chance, at 23 years of age Genevieve Barr is already hurtling towards the career as an actress she's always dreamed of. **Cathy Reay** tears the Yorkshire lass momentarily away from her new whirlwind life to see if she's enjoying the ride

**S**he has completed a degree in history and English at Edinburgh University, taught classes of school kids, is recognised as one of the best hydro-divers of her age in the country and now Genevieve Barr is putting all her talent, time and passion into one pot to chase her biggest dream yet: to be an actress. And, at 23, she's already landed her first big job.

"Acting has always been in me, even when I was teaching; they are essentially very similar as you're trying to hold the attention of a room full of people," she explains. "I have always been passionate about it but it wasn't until I started going for auditions that I realised it is what I want to do."

Genevieve is midway through her first day of interviews publicising *The Silence*, an upcoming four-part BBC drama in which she plays the 18-year-old lead character Amelia. This is a pretty huge accomplishment for any actress, particularly one that is unknown and has not had professional training.

"I wasn't looking for it at all. A friend asked if I wanted to audition for *The Amazing Dermot*, a one-off comedy showcase for Channel 4. I got the part, a very small role, and then from that the writers contacted me again to say they were looking for a deaf actress for a BBC drama and would I like to audition?"

Genevieve, having just started a Masters in Leadership at the Institute of London, rushed frantically between classes and auditions, finally scoring the part after the third round.



"I read the script and completely fell in love with Amelia, and the more auditions I went through the more I felt like I wanted to act rather than teach."

**The writers contacted me again to say they were looking for a deaf actress for a BBC drama and would I like to audition**

*The Silence* centres on a murder Amelia accidentally witnesses and the corruption, lies and danger she and those around her subsequently face. It is a tense, thrilling drama in which disability is also heavily addressed; it

focuses not only on what Amelia happens to see but also on her newfound ability to hear after she is fitted with a cochlear implant. Genevieve says Amelia's reaction to being able to hear is very different to her own: "I prefer the hearing world because that's the world I've grown up in but Amelia prefers the silent world, because that's the world she grew up in. I had to take out my own hearing aid to film, which meant I couldn't hear anything, but it was actually an asset to my performance because I got to understand her even more deeply."

Joining an incredibly established British cast including Dervla Kirwan (who recently starred opposite Colin →





Farrell in the film *Ondine*) and Gina McKee (*In The Loop*) and with the production company that brought *Skins* and *Shameless* to television at the helm, Genevieve said it took a while to get used to the thrill of working on such a big project.

"My first week of filming was largely with Gina and the first big scene I had with her was in this tea room, where she smacks me around the head. So, having just shook hands and said pleased to meet you, we immediately dove into filming that, 20 times, and then as soon as we finished we had to do a really happy scene. She was so normal between each scene whereas I was feeling a bit angry, plus I had a really sore head!"

Although it was sometimes awkward walking around the set without her

hearing aid in, the young actress said that she was surprised by the inclusivity of her colleagues. "It was nice how I don't think any of them saw me as a deaf actress so much as

**She spent her early years believing that it wasn't really possible for someone hard of hearing to be successful in the acting world**

someone that had never really done that much acting before. It was more my lack of experience that was unusual to them," she says.

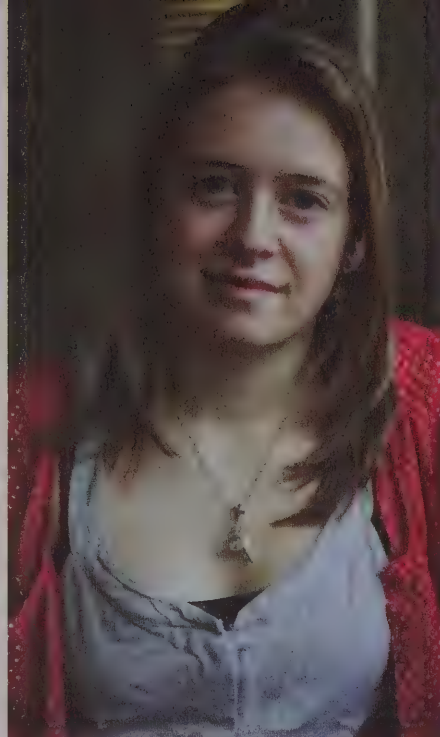
Surprised, perhaps, because she spent her early years believing that it wasn't really possible for someone

hard of hearing to be successful in the acting world. "In school plays I was always encouraged to go for leading roles but I would audition and then not get them and I didn't know whether that was because of my disability, that I wasn't coherent enough to deliver to a hearing audience, or if it was because I just wasn't a good actress," she explains.

"Maybe it was my confidence or maybe I thought it was too much of a risk to throw myself into something that I had a very small likelihood of being successful at."

Consequently Genevieve looked to alternatives, and found a huge passion for teaching. After university, she joined the Teach First scheme and ended up working in a school recognised as one of the "roughest"





JAMIE TROUNCE

in England. "I wanted to become a leader, to show my disability wasn't going to be an issue for future employers and I thought that by doing something like Teach First I could prove that, having gone straight into the classroom without prior teaching experience, I could handle a job of any responsibility.

"I found myself plunged into a school of 900 pupils that I'd been told were 'a living nightmare'. They took advantage of my deafness in that it was the obvious thing to pick on but I didn't take offence at that because I was anticipating it. I had overcome whatever struggles I'd had with my disability and it didn't have to dictate the rest of my life or who I would be."

Genevieve is incredibly determined to

never let her impairment stand in the way of what she wants to do. She's thrown herself into acting classes and speech therapy, the latter because she wants "people to be more open to the idea of having a deaf actress in a hearing role", and now with *The Silence*

about to air she's incredibly excited for her promising future onscreen.

"Getting *The Silence* has completely plunged my world into disarray; I have no idea what I'm going to be doing next. The world is your oyster, you can do whatever you want to do; I'm incredibly passionate about acting and I think there's always been something inside me that wanted to act but you can love so many things, there doesn't have to be one thing you're limited to; I am open to any prospect and opportunity that comes my way.

"I want to go on and be the best actress I can be, it doesn't matter what role it is as long as I get the opportunity to do the best I can. It's a challenge; bring it on." ■

• *The Silence* will air on BBC1 in May

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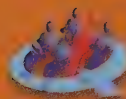


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1.9 TDi man & auto from 159g/km

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# Screening out prejudice

DATE

There's been a concerted campaign in recent months – including on the pages of *Disability Now* – to get more disabled people onto the small screen. But how has that pressure translated into increasing numbers in off-screen production roles? **Paul Carter** reports

**T**elevision is changing. When *Cast Offs*, a show starring and written almost exclusively by disabled people hit the nation's screens last year, it was lauded as a landmark moment – a watershed moment for disabled people in TV.

But dig a little deeper, and it becomes apparent that there is still a

long way to go before disabled people find themselves on an equal footing in terms of programme making, covering roles such as production, researching and screenwriting.

Clare Morrow, Network Manager of the Broadcasting and Creative Industries Disability Network (BCIDN) says that the industry is working hard to improve

the environment for disabled people.

"I think that we've come a long way in terms of it [disability] perhaps being a barrier," she says.

"I think that production departments are now open to the idea of having disabled people as part of them, which was probably not the case, generally, five years ago."





CHANNEL 4

“‘I don’t have days off sick and I’m very reliable but I can’t do all the things that everybody else can do.’ They then turn around and say ‘we don’t employ somebody with a disability’. I’ve had that three times”

few years and Channel 5 recently took on their first ever disabled trainee on a programme called *Milkshake!* There have been some considerable successes.”

Indeed, there seems to be almost unanimous praise for the work done by the industries’ big hitters – particularly Channel 4 – to increase off-camera diversity. However, most people agree that such schemes can only target a small part of the problem.

Kate Monaghan is development director of and partner in Mark Three Media, an independent television production company based in London.

“I think that the training schemes that the BBC and Channel 4 do are excellent, and I got into the industry through the Extend scheme which gave me an amazing first job on *Blue Peter*,” she says. “It was absolutely wonderful, but the problem comes when you’re looking for retention after those schemes.”

Such schemes undoubtedly provide opportunities for disabled people to break into the industry that did not exist in such numbers even a few years ago. However, there are bound to be more applicants than there are places, and even those that do make it through are not guaranteed full-time employment upon completion of the schemes.

This leaves many disabled people facing barriers to entry. The television industry traditionally has a very defined ➔



CHANNEL 4

**Top: *Cast Offs*, above; *How to Look Good Naked... With a Difference***

“I think there’s much more openness and willingness. Do the statistics support that we’re getting somewhere? Well I think it’s a very slow burn thing.”

What’s clear is that the industry has made great strides to improve more routes of entry for disabled people into the industry, with the major broadcasters leading the way.

“One of the key things is that there

have been some fairly extensive schemes run by some of the main broadcasters,” says Clare.

“BBC run something called Extend, Channel 4 have the Diversity Production Scheme and have done a couple of other initiatives involving specifically disabled filmmakers.

“ITV have had something called Enabling Talent, which they’ve run for a



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career path. Most people start out in the role of “runner”, which can involve everything from making tea to helping on shoots, before progressing onto researcher and then production roles.

“The amount of disabled people that I’ve met that broke into the industry without being on Extend, or without being on a Channel 4 scheme, I think I could only name one person,” says Kate.

“The first job is a runner. If you can’t be a runner, and you can’t run all over the place and carry everything, be the tea boy or work the 12 hour days for no money that you have to do, how else do you get started?”

Nikki Fox has worked in many of the behind-the-scenes roles. She started out on Channel 4’s trainee scheme as a junior researcher and went on to work for Maverick TV as a researcher and associate producer before doing some co-presenting on the recent disability-themed *How to Look Good Naked... With a Difference*.

She says that she would have found it extremely difficult to have followed the traditional route into the industry.

“What would be scary is if I was running because you have to be quite physical. I think the scheme recognises that some disabled people can’t necessarily start off as runners if you’re not as physically able, so it cuts out that whole stage. It gets you straight in as a junior researcher, which then leads you into being a researcher and so you get left feeling quite equipped.”

Clearly, there still needs to be a shift in attitudes among production companies, many of which are still struggling with embracing the idea of working with disabled staff.

“When you’re going out into the world after these schemes, you’ve got a handful of production companies who are really good about disability, and they understand it and they make



the effort, and places like Maverick Television and Love Productions are superb,” says Kate.

“But, equally, there are hundreds of production companies who can’t face it and can’t stand it.

“There have been production companies I’ve been to, been offered a job, and then said, ‘I’ve got something to tell you, I’ve got a disability, it probably won’t affect you but it means I can’t hold a boom, I might have to have a bit of time off to do physio or have doctors’ appointments. It’s not going to affect you that much, I don’t have days off sick and I’m very reliable, but I can’t do all the things that everybody else can do’. They then turn around and say ‘we don’t employ somebody with a disability’. I’ve had that three times.”

Jack Thorne was a co-writer of *Cast Offs*, the drama which first aired on Channel 4 late last year. He says that the industry is improving, but that the economy and the decline of advertising



**Above: Kate Monaghan. Left: Nikki Fox**

revenues is holding things back.

He says: “My disability is invisible, so production companies that hired me had no idea what my requirements were. They’re now very good around my requirements because I do have a few, and they do look after me very well but I wasn’t hired with that in their head.

“If the economic climate was better, then I think doors would be being pushed down faster. The fact that the economic climate is not great means that telly is not in a good place. They’re not making stuff – it’s not a case of not making stuff with disabled people, it’s just a case of not making stuff full-stop which is more of an issue.

“I genuinely think that people want to push down the barriers now and I really think that British TV being in the place that it is is something to be celebrated, and that they’re really getting it right at the moment in a way that other countries haven’t.”

Television, by its nature is a freelance industry. Many jobs involve working on individual series or programmes, often on short-term contracts. When production on a particular show comes to an end, so does the job and that person then has to move on.

This aspect of the industry can pose particular challenges for disabled people, particularly those with access needs as companies may be less willing to fund reasonable adjustments.

However, a new pledge drawn up in conjunction with BCIDN and the Producers Alliance for Cinema and



Television (PACT) aims to move companies to a position where they have to demonstrate their willingness to work with people with a disability.

Clare Morrow of BCIDN explains: "The pledge is something that independent companies have to sign up to and pledge that they will take a certain number of actions to increase the diversity of their workforce.

"It's moving to a position where it's unlikely they will get a commission from one of the major broadcasters unless they have signed up to the pledge.

"This seems to have pushed at a fairly open door, and lots of independents have signed up to the pledge very willingly."

Jack Thorne feels that if the on-screen representation of disabled people continues to improve, that too

**“It's very important to see difference. If seeing disabled people on-screen encourages other disabled people to get into the industry then that's an amazing thing”**

will help increase the numbers who want to take up a career behind the camera.

"The walls are coming down," he says, "and the likes of Peter Mitchell and Mat Fraser will be a real boon for people off-screen."

Nikki agrees: "It's very important to see difference. If seeing disabled people on-screen encourages other disabled people to get into the industry then that's an amazing thing."

Clare says that there has been a "significant step forward" in convincing not just production companies, but also disabled people.

"What's slightly more difficult is finding lots of suitably interested, able, aspiring people to work in the industry. There's a bit of a mismatch. The reason we've been focusing quite a bit on the screen is because clearly if you do more on the screen, and you see more disabled people on the screen, then the hope is that more disabled people will think 'oh, actually this is an industry that I can be part of'."

"Without diversity", says Kate, "we don't make the best programmes that we can make because it's all about the lives of middle class people looking down on lower class people. We don't get the authentic voices." ■

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# yourviews



## Bader legend recalled

I met Douglas Bader once when I was in the police. A sports car had broken down on the busy A6. All that was visible of the driver was a pair of legs sticking out from under the car. My companion and I tried telling him the danger he was in, but he only said: "I don't care. I can't be hurt anymore."

We insisted he come out from under the car, and asked who he was. He threw us his driving licence and asked us to help him get to Morris Grange, a Red Cross hospital for the disabled 14 miles away (and outside our county), where he was due to be guest of honour at a fundraising event.

We said we were in a police car, not a taxi, but we took him anyway and asked him to say nothing. As no good deed goes unpunished, he wrote to thank our Chief Constable, who gave us a bollocking for leaving our patrol area.

Douglas Bader was a hell of a character who didn't care about his own problems and preferred to help others whom he said were "more unfortunate".

**Name not supplied**

Wot, no Ian Stanton on your top legends list? For shame! Who could ever forget the lyrics to "I remember Douglas Bader" and Bader made the list!

**Maggie Cameron, by email**

## Distressing assisted suicide story should be put to sleep...

As a disabled person I have to say how fed up I am at seeing stories on assisted suicide in pretty much every newspaper, magazine and on disability websites.

I have multiple sclerosis, there's no cure and my condition will deteriorate, but I try to take a positive view on living my life to the full while I can.

Why, then, must I keep reading about alternative ways of killing myself (or of someone killing me) if I choose to take this path in the future?! I think it quite right that someone should have the right to take their own life (disabled or not) should they so choose, but does everyone have to debate it incessantly?

It doesn't help disabled people live positive fulfilling lives and is quite frankly depressing to them and their families.

**Kelly John, by email**

## ... or kept awake

I feel people do have a right to decide to die, when competent to do so. I have a blood-borne terminal virus and I'm not suicidal, but I have signed a DNR statement to say that I would not wish to be resuscitated if I wouldn't have a good quality of life.

I wouldn't want to end up like my mum did, trapped in a useless body with an active brain.

**Name supplied, by phone**

## Readers' experiences of tourism: request for research help

I'm a Masters student at the University of Exeter studying marketing and I'm currently undertaking my dissertation project on disability and tourism.

I'm specifically looking at the use of disabled people in tourism marketing campaigns and travel brochures, and also the information that disabled tourists would like to find in travel brochures and campaigns.

If readers have travelled within the last five years, either domestically or internationally, I'd greatly appreciate it if they'd be willing to help me with my research by completing a short questionnaire on their views and experiences.

To receive a copy of the questionnaire, please email me at my university email address which is [slw225@ex.ac.uk](mailto:slw225@ex.ac.uk).

Thank you for reading this letter and thank you in advance if you wish to help.  
**Sarah White, University of Exeter (MSc in Marketing)**





## Four wheels good

I'm sick and tired of people like Helen Smith slagging off mobility scooter users. Typical! Have a pop at disabled people because they can't answer back.

She was wrong to say that a woman on a scooter failed to brake and ran into her and her mother. Scooters don't have brakes: you just release the controls, so all that happened was that the woman didn't release the controls in time. One

question what she and her mother were doing.

Why doesn't she pick on women with prams, with phones and cigarettes, using buggies as rams? Or old people on pension day in M&S smacking me in the face with their handbags?

If people respected that scooter users are disabled these accidents wouldn't happen.

**Mrs Findlay-Judge,**  
by phone

## Good morning. How can we not assist you?

"Take it or leave it" seems to be the customer-service attitude of companies supplying assistive products to their disabled customers.

We have to accept third-rate service for the delivery of third-rate products and we're not allowed to get angry.

Are we always supposed to be docile and nice while putting up with this insult?

Case in point: does anybody know how I can buy replacement ferrules for Progress crutches? I'd really like to not have to use their only British supplier.

**Ben Thomas, by phone**

## Changes at Jobcentre Plus go undetected

Have you or your readers heard about the changes being made to the way Jobcentre Plus handles benefit payments?

The days we are paid are being changed, and

payments are now going to be made fortnightly and not weekly. This is all due to happen in May, but I've not seen it commented on.

**P R West, Angus, Scotland**

jobcentreplus

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### → Have your say

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- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)



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## Never mind the quality... value the life

Those who argue in favour of assisted dying are, says **Andy Rickell**, joining in with a society which is all too ready to regard disabled lives as without value

**T**he Dignity in Dying brigade aggressively talk up traditional negative stereotypes of disabled people to promote assisted suicide. This worsens the climate within which disabled people must live, and forces activists onto the back foot. We need society to think differently about the quality of all human life.

Firstly, let's nail the lie that life's pattern is about moving from being a dependent child to being an independent adult, so that needing personal support due to impairment or old age is seen as a failure – becoming “a burden”. This is eugenic thinking and anti-human – only valuing people for what they do, not also for who they are.

We need to remind society that we are all inter-dependent – there are times in all our lives when we function best with the support of others – always as a child; ultimately

as an old person if we are fortunate to live long enough; for some people at additional times too as a result of permanent or

**We need to remind society that we are all inter-dependent – there are times in all our lives when we function best with the support of others**

temporary impairment, and for all of us when we enjoy the interaction with family, friends, colleagues, neighbours, and all those who supply our material needs. We should rejoice at how all individual achievement arises because of the support we receive over our whole lives from others. All society's successes are jointly achieved! So we need to recognise the value of both giving support and of receiving it too – no

longer a “burden” or a “carer” but all of us citizens experiencing the true meaning of life together, whether in families or in the wider community.

Secondly, we need to value life all the more when it is under threat, and particularly when it is others' lives at risk. Whether one sees human life as a gift from God, or a random gift, it is nonetheless a gift of immeasurable worth. To devalue any life is to devalue every life including our own. So it is our behaviour when another's quality of life is threatened, including its existence, that is the touchstone that proves our own humanity. For instance, when a disabled person indicates they want to commit suicide, our collective first reaction

must be to strongly encourage them to think otherwise, and to offer them every support that might help them to improve their quality of life both in reality and also as they see it – that is what we would do for anyone else. Any failure on our part to act in this way adds to the individual's belief that indeed their life is not worth prolonging.

Finally, we need to challenge what people mean by “quality of life”. We need to encourage people to measure life's quality positively, rather than that only a fully functioning adult life is OK and that everything else is somehow much worse. A study of very impaired children showed that they felt their quality of life was as good as anyone's.

### → Have your say

- write to us **Disability Now**, 6 Market Road, London N7 9PW
- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)
- phone us 020 7619 7323



# asktheexperts

you ask, they answer

As ever, we have a team of experts, disabled and non-disabled, to answer your questions on the issues that affect our lives. Whether you need advice on choosing a wheelchair-accessible vehicle, how to make a claim under the Disability Discrimination Act, or resolving a difficult personal issue, one of our panellists is sure to be able to help. Here are some brief introductions.

## TRAVEL

### ANDY WRIGHT



Andy is a disabled travel industry professional, with over 25 years' experience. He's the managing director of Accessible Travel, a specialist tour operator providing holidays for people with mobility impairments.

## RELATIONSHIPS

### SIMON PARRITT



Simon is a qualified chartered counselling psychologist. Disabled himself, he studied psychosexual therapy for three years and has a professional interest in stress and anxiety disorders.

## ACCESS

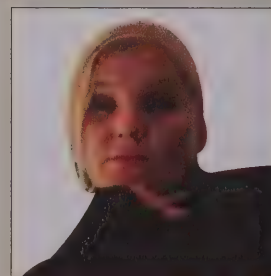
### AGNES FLETCHER



Agnes is a disability trainer and consultant who can find solutions to access problems. She has helped readers on subjects ranging from finding and hiring equipment abroad to issues with accessible public toilets.

## TECHNOLOGY

### LÉONIE WATSON



Léonie is a computer consultant and works for the digital consulting firm Nomensa. She specialises in adaptive technology and can answer questions on how to get you connected and best able to use the internet.

## FINANCE

### DAVID CLARKE



David is a senior partner with Clydesdale Bank, with 18 years' experience in the banking industry. He has also worked for HSBC and the Royal Bank of Scotland.

## HOUSING

### KATE SHEEHAN



Kate is an occupational therapist and director of Better Living, a company set up to work with mainstream manufacturers to meet the needs of the ageing population.

## LAW

### DOUGLAS JOY



Douglas is senior solicitor at the Disability Law Service, and he gives advice on disability and the law. He specialises in questions on discrimination and disability.

## BENEFITS

### SELINA MILLS



Selina works at Citizens Advice Bureau and has a team ready to deal with any concerns you may have over benefit entitlement, debt or other money matters.



## TRANSPORT

HELEN SMITH



Helen is a *Disability Now* columnist, as well as campaigns and policy director of disabled motorists' lobby and campaigning charity Mobilise.

**Q** I'm a wheelchair-user and the lease on my Motability car is up in May. My daughter drives for me and as she has had three claims on the insurance Motability is not renewing the lease even though the claims were not her fault. What can we do?

**Christine Atkinson, by phone**

**Helen Smith says:** Although you say the claims were not her fault, I presume that it was Motability's insurance –

RSA Motability – who had to pay up. They will work on a no-claims rather than no-blames basis and since they've had to pay out three times, I'm sure you can understand why they wouldn't want to renew your lease.

It may seem a little harsh but Motability has to keep its costs down and if drivers claim on their insurance

multiple times, their costs rise and that has an adverse affect on other customers.

If there is someone else who could drive your car for you, you could ask Motability if they would renew your lease with a different driver. Your only other alternative is to use your mobility allowance to buy your own car and find your own insurance.

→ **If you have a question for our panel**

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- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)

# Who's your DISABLED LEGEND?

In our April issue, we asked you who you thought had done so much as a disabled thinker, performer, activist, entertainer or sports star that he or she deserves the status of **LEGEND**?

We presented 50 contenders who've shaped the way disabled people are viewed and treated.

## We're asking you to vote for one of our 50 likely legends.

Take a look at last month's issue, or go to [disabilitynow.org.uk](http://disabilitynow.org.uk), and decide for yourself.

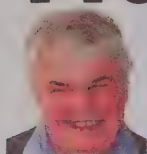
Is it Stephen Hawking or Stevie Wonder, Tanni Grey-Thompson or Henri de Toulouse-Lautrec, Beethoven or Baroness Campbell, Spike Milligan or Bert Massie? Cast your vote online, or write to FREEPOST, Disability Now (envelope but no stamp required).



# pete's place



## Way off poll position



When it comes to voting, even the keenest of disabled people are heavily discouraged from exercising their right to vote, says **Peter White**

**L**iz Ball is dead keen to vote; she's a political animal, and wants to have her say. And, if you listen to the politicians and the pundits, she's just the kind of young voter we're afraid of losing to apathy or disgust, as fears grow that the percentage of those voting may fall below 60 this time.

And yet, and as usual, we'll be making it as hard as possible for Liz to cast her

vote. With the dual disabilities of blindness and deafness, Liz will get her Braille manifestos, if she gets them at all, well after everyone else (ironic, as she's one of the few people who will probably bother to read them). If she wants to go to the polls (and she does) she'll need an interpreter who knows the deaf-blind manual, something it can take more than three weeks to arrange

(and how much prior notice do we get for an election?). The difficulties of getting to the polling-station will almost certainly lead Liz to opt for a postal vote, but even if she does that, she won't be able to conduct her vote with the privacy everyone else will take for granted. She's very unlikely to receive her polling information in an accessible form, and will therefore need the assistance of her

interpreter to make her mark in the right place. Had she gone to cast her vote personally, she might well have encountered a polling-station pretty inaccessible to many other disabled people: in schools and church halls, up or down flights of steps, down country lanes, asked to vote in places where you couldn't swing a cat, let alone turn a wheelchair, or which aren't served by public transport.

The fact is that despite a swathe of campaigns, anti-discrimination legislation and local authority duties, it's another of those areas of British life where we continue to worship at the shrine of antiquity, and that great British motto, "it's how we've always done it".

The plain fact is that it's now much easier to cast your vote between several indistinguishable manufactured girl- or boy-bands on *X Factor*, than it is to exercise your democratic right to vote for the candidate most likely to improve your life. The idea that we might vote electronically from the comfort of our homes, rather than trek across a ploughed field on a wet Thursday evening, goes against all our puritanical principles!

One of the most common words used by leaders and candidates is "change". Pull the other one!





# guestcolumn

## Unsuitable cases for treatment

While campaigners call for more acceptance of mental illness, the definition of what it means is being broadened. This, says service user **Maureen Sellwood**, is having a direct effect on provision for and perceptions of severe mental health conditions

**A**s a long-term user of psychiatric services I have become increasingly concerned about the current trend in health and government initiatives to label everyday stress and even basic unhappiness as mental illness. The latest edition of DSM-5, the psychiatrist's bible, has included a number of conditions previously seen as commonplace difficulties. They include such things as overeating, gambling, internet addiction and even PMS. Premenstrual stress affects some 50 per cent of women who are apparently now to be included as "suffering from mental illness".

I have attended counselling groups in my local psychiatric day centre alongside people who are having difficulty getting on with their colleagues at work and those in unhappy relationships. These experiences may be stressful, a certain amount of stress is an inevitable, even necessary, part of human experience – it



cannot be compared with severe psychiatric problems.

Charities like Rethink and Mind have campaigned tirelessly to counteract stigma and prejudice against people with mental health problems. They are having considerable success, and can rightly be proud of their achievements. However, in their zeal to depict all of us as dealing with "normal" complaints they have moved the goal posts that define mental illness. Mental illness is a very broad term and, of late, it has become broader still. At one time it would never have been suggested that someone distressed because of a job loss or bereavement was mentally ill.

Although severe stress can play a part in triggering

severe mental illness in susceptible individuals, placing human unhappiness alongside conditions such as schizophrenia has resulted in

**A certain amount of stress is an inevitable, even necessary, part of human experience – it cannot be compared with severe psychiatric problems**

the needs and experiences of people living with serious mental health problems being undervalued. Complex needs are now in danger of being treated with short courses of counselling or

even pleasant walks in the countryside – such treatments may be helpful to those coping with the vicissitudes of life but are certainly not appropriate for people dealing with a terrifying life-long condition. When I have been "unwell" as they say, I have, many times in the past, felt compelled to run energetically for miles through city and open fields alike – it didn't seem to improve my mental health one jot.

Because of those, albeit laudable, initiatives to have mental illness seen as a common and "normal" experience, those of us who are most in need of help are being sidelined, threatened with the loss of benefits and support and left to a life trying to deal unaided with the trauma of psychotic illness.

Ironically, at the same time as this redefinition of what constitutes mental illness is taking place, there is public outcry, fuelled by the tabloids, against "violent mental patients" being allowed to wander the streets. There are calls to have those of us who live with psychosis locked away for life but what we really need is proper care and support, support that is increasingly being denied us as a consequence of a now blurred and hazy definition of mental illness.



# upclose & personal



## Holding on to family ties

For many young disabled people, going off to college brings the first real taste of independence from family. But for **Anuya Pai** (pictured right), things were slightly different as she adopted a different approach to meeting her care and support needs

**O**n my first day of university in 2007, I was like any other new student; apprehensive and excited about what lay ahead in the days, months and years to come. There was only one thing that made me different from my peers: I had my dad by my side.

I have had cerebral palsy for my whole life following complications that occurred as a result of my premature birth. CP is a neurological condition that affects

movement and coordination. It has varying consequences and degrees of severity. In my case, I am unable to stand or walk and use an electric wheelchair.

I had always known that I wanted to attend university. I felt that although I might be lacking certain physical capabilities, I had been given a good brain and I intended to use it.

When I was accepted into university at 18, my parents and I began considering the care options that would be

available to me during my time as a student in higher education. After much thought, my parents concluded that they were uncomfortable with the idea of my being tended to by a stranger and so the decision was made that my dad would leave his job to attend university with me as my carer.

We were fortunate enough to be provided with wonderful accommodation that includes a walk-in shower and adjoining rooms

so my dad is just a call away if I need him during the night. This has proved to be very helpful over the years, particularly during my first year when the fire alarm was regularly set off accidentally in the early hours of the morning and everybody had to exit the building in their pyjamas!

The idea of taking a parent to university with you might seem strange to students who relish the freedom of living away from home for the first time and view this as an opportunity to cut the proverbial apron strings. I am sometimes asked by people if I find my dad's presence to be a hindrance in social situations. It may come as a surprise to know that, in fact, friends and staff alike have embraced my dad wholeheartedly. He is met by others, not with bewilderment, but rather, admiration for the depth of his sacrifice.

It is true that my time at university may be in stark contrast to that of other students, but it has been no less enlightening. I have learnt a great deal about the things of which I am capable and forged meaningful friendships. The fact that my dad has been with me every step of the way just makes the experience all the more special.



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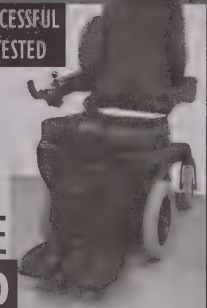
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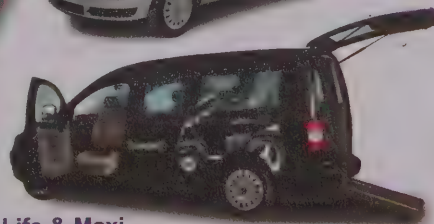
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**B**ournemouth bred Roxanne Louise who has cerebral palsy has just been signed to Sinclair Model Management who represent Britain's Missing Top Model winner Kelly Knox. Roxanne Louise has also been made officer of their Models of Diversity campaign whose mission statement reads: "Our models convey that beauty comes in all colours, shapes and sizes and you too are entitled to 'feel beautiful' within your own skin – the word 'beautiful' should not be designated to the select few but to everyone."

This is an empowering concept for all women but particularly those of us who're disabled. If true diversity was embraced by the media it would dramatically improve many people's self-esteem and quality of life and Roxanne Louise well knows how desperately change is needed.

"I use a wheelchair to stay mobile and get spasms in my lower limbs and hands. People treat me like I'm thick, I get sat on on the tube, I get asked if I can have sex by random strangers and it's a NIGHTMARE buying shoes!"

I've experienced similar responses myself, especially strangers asking about sex, but now I wear red lipstick, something tight and a slight glower and only get asked intimate questions when invited. Roxanne Louise attributes her own image-epiphany to Gok Wan.

"I used to hate my body! I loved fashion – on everyone else! I was the girl in the tartan trousers three sizes too big and three inches too long teamed with a guy's T-shirt held up by braces, big black eyes and the lines down my face to match (cringe). I was always the rebel at school! I realise now I wanted people to stare at me and not the wheelchair. Then I started watching Gok and started pulling at the excess fabric to discover a waist and pretty nice cleavage. Gok restored my confidence and love for



MICHAEL CHEETHAM

## Roxanne Louise is modelling diversity

"If you don't have the courage to shout, give me your words"; 19 year-old model Roxanne Louise Steel is on a mission to change the face (and body) of the media and tells **Lara Masters** how we can all help

clothing and helped me feel sexy – now you try and get me outta River Island!"

Roxanne Louise has her sights set on being the face of a high-street brand like River Island but has had to jump a

few hurdles and get out of her own way to begin to realise her ambitions.

"My mum couldn't cope with my disability so she abandoned me. I was looked after by my Dad and went to a





MICHAEL CHEETHAM

special school from two and a half until the age of sixteen. I excelled in sport and did a BTEC at Brockenhurst, a mainstream college. In hindsight, I should have taken art so I could have gone on to do fashion but didn't want the carer I would have needed for fear of looking cripple-like."

Post-college, housing problems found Roxanne Louise living in an old people's home rather prematurely but now she's happily settled; "I have my own flat, a perfectish boyfriend and a rabbit. I'm looking for a job to go alongside the Models of Diversity campaign and want to study fashion so I can be a personal dresser/fashion journalist as well as a model!"

I'm guilty of being jaded by years of hearing the media, fashion and advertising industries pay lip-service to

being more inclusive and doing nothing about it, but discovering a model agency which prioritises diversity has re-ignited my hope that shifts are actually possible – especially with the effusive and motivated Miss Steel as ambassador.

"With the Models of Diversity campaign I want to get real people into our media, to promote being healthy as beautiful to stop girls from starving themselves, and to stop people being scared of disability.

"The media is by the people for the

people! I urge *Disability Now* readers to write to magazines and say you want to see bigger models, shorter models.

When you're shopping, tell staff their pictures aren't of real people and that puts you off buying – then give them our details! Your comments could make a huge difference and may even save your future granddaughter's life!"

It's hard not to be infected by Roxanne Louise's insightful enthusiasm and brilliant, guru-like slogan-ism; "We are real, so why should we accept any imitation? Request Reality, Demand Diversity!"

And of course Roxanne Louise is absolutely right; it's up to us all – it takes a village – or perhaps a Facebook group!? Join "Models of Diversity" on FB today and let's be the change we want in the world! ■

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Sally, Michelle's mum



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livingnow

If there's such a thing as Russian chic, then St Petersburg has it, as **Ivy Broadhead** found out when she took advantage of the closeness offered by a student placement in Helsinki to make the trip by bus across the old forbidding border

In search of

# Mother Russia





There is something just a bit magical about going to Russia; vast, far away, rather mysterious, and with awkward enough visa requirements to make you wonder why they don't really seem to want you in their country; it must be something really good, right? Or really bad.

We got an overnight bus from Helsinki to St Petersburg, in part just because it seemed rather exciting to be able to get on a bus and wake up in Russia. And it was. As we juddered in around 6.00am, we got to see the city waking up, its beautiful old buildings slowly illuminated by the sunrise, and the big wide streets mostly empty. Of course, if you have more than a student budget, taking a train or flying would be far more comfortable, faster, and probably much more accessible, but for us the bus worked.

Keen to offload our bags, we headed straight for our hostel, tucked behind the Kazan Cathedral on Nevsky Prospect, which is a little way south of the Neva River. Cuba Hostel was cheap, bright and friendly, in a cool and studenty kind of way, and staffed by incredibly helpful bright young things who were keen to direct us to good places to eat and drink nearby, and on one morning even came for

breakfast with us. When you've been pointing and guessing for four days having a native Russian speaker on hand is very much appreciated.

The first thing that will strike you when you get into the city is just how beautiful, how grand and how very un-Soviet the city feels; all tall, imposing buildings, glorious old churches and picturesque little bridges. The people perhaps fill the stereotypes a little better; lots of glamorous Russian

**Cuba Hostel was cheap, bright and friendly, in a cool and studenty kind of way, and staffed by incredibly helpful bright young things who were keen to direct us to good places to eat and drink nearby**

women in furs and stilettos smoking slims, along with plenty of grumpy Russian guards and police in fur hats, with guns underneath their trench coats. Despite this potentially ominous presence, it is a lovely place just to wander around, although the bitter winter cold and guidebook full of circled must-sees kept us from

### Did you know?

Apparently St Petersburg celebrates its birthday on May 27th every year. With almost 4.7 million inhabitants that's got to be a pretty big cake.

spending too much time aimlessly. There really is something for everyone's interests; architecture, history, literature, ballet, opera, art, the military, gardens, as well as surprisingly good food and some lovely, underground kinds of bars. It would surely be rude to leave without sampling at least a little vodka after all?

Having weighed up the appeal of opera versus ballet, we decided on the first and booked tickets before we arrived, spending our first evening in Russia watching Swan Lake at the Mariinsky Theatre. Even after a night of very little sleep, it was beautiful and elegant, and almost as captivating as it had been when I first saw it, aged seven and very excited. We paid the equivalent of about £30, which was probably more than we spent on food over a couple of days, but we got what we paid for.

It would be impossible to try and tick off all of the churches in St Petersburg, but in our five days we managed quite a ➔



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Left: Church of the Saviour of the Spilled Blood; above: Kazan Cathedral





IVY BROADHEAD

### The view from St. Isaac's Cathedral

few. Near our hostel were the Kazan Cathedral, an elegant pillared building apparently modelled on St Peter's in Rome, and the clumsily named Church of the Saviour of the Spilled Blood, built on the spot where Alexander II was murdered in the 19th century. The second is the one you've most likely seen on the postcards, glittering, multicoloured onion domes housing an amazing mosaic interior of biblical scenes. From a distance, it looks like it could be built out of children's sweets, and up close it still retains an element of the fantastical, which makes it very strange to learn that in the Soviet era it was used to store potatoes. Over the River Moyka lies the third church I'd recommend, the gilded St. Isaac's Cathedral. A perfectly beautiful church in its own right, what really makes this one worth mentioning are the

spectacular views that greet anyone who manages to tackle the winding stairs leading up to the top of the dome. With a long standing Muslim population, St Petersburg also has a huge central Mosque, which looked very impressive from the outside, although non-worshippers are not permitted to enter.

We dedicated one afternoon to the Peter and Paul fortress, which was St Petersburg's first settlement back in the day but is now pretty touristy. It was interesting to see the fortress and to learn more about the city's origins, and we did get to see some pretty impressive marching routines and gun shuffling from an army band, but if we had been pressed for time it probably would have been one to miss.

For art lovers, of course the Hermitage is a must; we could have spent our whole five days there and probably not seen everything, but instead we spent a good half day there and saw some beautiful works of art, from Miro and Picasso to Rembrandt and lots in between. The buildings

themselves are amazing, although not quite as impressive as those at the Russian Museum (which includes the Mikhailovsky Palace), again near to Nevsky Prospect. All marble pillars, gold metalwork, intricately patterned

**Salmon, caviar and rye bread are big players in Russian cuisine, but there are also lots of sweet, dense pastries on offer**

wallpapers and staggering ceiling decorations, the building occasionally threatens to overshadow the artworks, and would be worth the entry fee alone.

We left with plenty more still left to visit; the Summer Palace and gardens, the Pushkin House beyond the river, and the Dostoevsky Museum to name but a few. St Petersburg is somewhere I would definitely go back to, although perhaps I'd wait until the Spring for my next visit; on more than one occasion we cut a wander short because it was just too damn cold, and spent a decent

### Did you know?

It is the most Northern city in the world with a population of more than one million people.



amount of time ducking into cafés to thaw numb fingers and toes.

With visas and transport to sort out before you get there, a trip to Russia may not be as cheap or simple as a mini-break to Paris, but once you get there things are generally very cheap, including museum admission, even taking into account the huge foreigner tax imposed on every ticket you buy. Souvenirs were of course overpriced and not brilliant quality, but we had some fun sifting through the market stalls and did come home with a few of the requisite Matryoshka dolls and colourful floral scarves, after a bit of good-natured bartering with the stallholders.

Food is also very cheap, and largely pretty good. Everywhere you go are quick, cheap Teremok blini stands and restaurants, which serve big pancakes rather than the small ones we call blinis in the UK, and with any filling you care to think of. Imagine a much more exciting, Russian version of McDonald's. Salmon, caviar and rye bread are big players in Russian cuisine, but there are also lots of sweet, dense pastries on offer, and a surprising number of sushi restaurants. Actually, perhaps not so surprising given the salmon and caviar fixation. One of our party was a vegetarian, and had feared she would be in for five days of bread, cheese and cabbage, but we did manage to find a lovely all-vegetarian restaurant, the Café Botanika near Chemishevskaya metro. It wasn't as cheap as some, but worth every rouble to get some vitamins inside us; we found some delicious Russian food, but light and healthy it was not, probably something related to how bitterly cold it was for much of our stay. We found a pretty good balance between eating in fancy restaurants and real Russian-style eateries, such as the place near to our hostel on Nevsky Prospect called Frikadelki. They served



**The Hermitage**

up hearty soups, porridge, pancakes and other traditional food to tables of Russians who looked like they were in for a hard day's work, and for 100rbls (about £2) you could find yourself pretty stuffed. As well as the sushi restaurants, we passed lots of French-style boulangeries and cafés, which were more expensive than the Russian places but worth a look if you get sick of blinis.

Having been spoiled by the luxury of being able to resort to English whenever my meagre Finnish fails me in Helsinki (which is often) it was a bit of a shock to realise how few of the people in shops and restaurants spoke English. There was a lot of pointing and gesturing involved in ordering in shops and restaurants, and there were a couple of times when we ended up

with something slightly surprising, but staff were generally pretty patient and good natured about it. I got nowhere with the Cyrillic alphabet, and had a couple of times where we ended up slightly lost, street signs being a bit tricky to work out from the Roman alphabet versions on our map. We did a lot of walking around, but the metro is fast and cheap, and quite simple to work out, especially compared to the Tube in London.

On reflection; cold, confusing, cheap, grand, big, strange, beautiful, old and modern all at once. Not an easy trip, in terms of access, language, or getting into the bloody country in the first place, but one you won't forget. I'm still under the spell anyway... ■

## INFORMATION

Visitors from most countries will need a visa to get to Russia. For a UK citizen in 2009 the cost was approximately £80, although it is cheaper for other countries within the EU. You can apply for a visa through a travel agent even if you aren't going on a package trip, which means you generally don't have to visit the embassy yourself. For more information go to [visitrussia.org.uk](http://visitrussia.org.uk)

We travelled by bus from Helsinki, but major airlines like KLM and British Airways do fly direct to St Petersburg from the UK. More information can be found on their websites.

IVY BROADHEAD



# tried&tested



## Waking up to the vibe

If you're a deaf or hard of hearing person looking for a decent new alarm clock with a vibrating pad, the HearPlus 333cl from Doro electronics could be for you says **Jamie Trounce**

**A**s soon as I got it out of the box, I could tell that the HearPlus 333cl is a much more fancy looking clock than my old one, which is grey and ugly. It has a white body with black face and white hands, making it quite retro looking.

Setting it up is a little complicated at first as I realised that when you adjust the time, you have to wait for 30 minutes for the clock to complete the time adjustment properly before you can test the alarm, otherwise you might think the alarm was not working.

Once the alarm is set, the pad goes off with perfect strength. It woke me up slowly and gently, with a long vibration.

On my old clock the vibrating pad is too powerful when the alarm goes off which I don't think is suitable for older people or those with heart problems. Every time I'm sleeping very soundly, the

alarm goes off and it vibrates like a hard fire alarm, which always makes me wake up suddenly with my body up in the air for a long second!

The pad itself on my old alarm clock is also a rather odd shape, almost like a flat egg, which is slightly uncomfortable as you can feel it under the pillow.

Occasionally, the pad on my old clock fell off my

**Once the alarm is set, the pad goes off with perfect strength. It woke me up slowly and gently, with a long vibration**

pillow while sleeping which made me late for work, with an unhappy boss waiting for me.

The HearPlus 333cl has a big low round pad with rubber feet, which prevent it from falling off my pillow.

The only problem I found with it is that it has a flashing light underneath



the alarm clock that is very weak so I never see anything. However, this is not that important to me as I only require vibration.

There are four different combinations of ways to wake you up— vibration only, sound and flash, flash only, and sound only – all connected with vibration if needed although as I already mentioned the flash is not very good.

As for alarm tones, there are low or high frequencies, though I have no idea how loud they sound as I am profoundly deaf. Finally, if you have a phone, you can connect your phone to the alarm clock so when the

phone rings, it will wake you up – which I think is a very good idea in case of emergency with your family/friends or anything else!

I would definitely buy the HearPlus 333cl as it is ten times better than my old clock without any hesitation.

### INFORMATION

HearPlus 333cl, vibrating amplified alarm clock costs £49.99 – to buy from [bigeasyphones.com/hearplus-333cl-51-p.asp](http://bigeasyphones.com/hearplus-333cl-51-p.asp) Also check other online and high street electronics stores





# Disability

## Listen Include Build

### Free Capacity Building Support to Small and Medium-sized Disabled Peoples Organisations (DPOs).

"The Pilotlighters were brilliant and went beyond the call of duty... It was immensely enjoyable... lots of ideas, great openness." – Disability Action in Islington.

Disability LIB is partnering with the charity Pilotlight to help DPOs build their capacity for strategic planning and long-term sustainability. Pilotlight brings together skilled professionals from the private sector and harnesses their talents to help small to medium-sized charities and social enterprises tackling disadvantage.

Pilotlight provides a uniquely managed capacity-building process that supports organisations in exploring their vision and giving them the skills to make it happen. It uses a hands-off coaching model so that its partner charities remain in control and get real strategic planning skills from their work with Pilotlight.

"We appreciated the opportunity to talk to people who take us seriously... and to think differently." – Disability Action Waltham Forest.

Pilotlight have worked with over 100 organisations in the last five years, including DPOs throughout the UK. The results are impressive. After benefiting from Pilotlight's support, organisations have reported better management and governance, more income and staffing, and greater impact on service-users. Two years after working with Pilotlight, the charities and social enterprises we support (The Pilotlight Effect '08) have:

- Increased the number of people reached by 57%
- Increased turnover by 54% (6 times the voluntary sector average)
- Improved services provided to individuals and communities by 60%

"With the help of people who bring some objectivity, Pilotlight gives you the space that you don't usually have as a DPO to think much more broadly about what the organisation does and where you want to get it to in the future." – Alliance for Inclusive Education (ALLFIE).

If you think your DPO could benefit from working with Pilotlight please contact Stephen Hodgkins at Disability LIB [stephen.hodgkins@disabilitylib.org.uk](mailto:stephen.hodgkins@disabilitylib.org.uk) or 0844 800 4331 for more information and an application form.

Or to learn more about how Pilotlight uses coaching and capacity building to help charities and social enterprises, please visit [www.pilotlight.org.uk](http://www.pilotlight.org.uk) or contact Helen Lang at [hlang@pilotlight.org.uk](mailto:hlang@pilotlight.org.uk) or 0207 283 7015.



LOTTERY FUNDED





## Consultation consultation consultation



While it's right and necessary for the Government to consult all parties to monitor if it's getting things right, when it comes to Blue Badges, things have gone too far

**O**h no! Not another Blue Badge consultation! When an email about another Blue Badge consultation arrived in my inbox in March, I thought I had a bad case of déjà vu.

After all, it was only in March 2007 that the last consultation on Blue Badges was carried out, and prior to this there had been a review in November 1999.

I originally thought I'd been re-sent the 2007 consultation, entitled "Blue Badge Reform Strategy". On closer inspection I realised the Government

was consulting again. This time the consultation document was called "Blue Badge Reform Programme".

After comparing this with the 2007 consultation, it seems to me that the new one is more interested in the finer detail of how changes should be made and how enforcement would work.

Now I completely understand the reason behind consulting but when you think that the first review was in 1999, it seems pretty amazing to me that we are still being consulted on changes over ten years later.

Although there have been

some changes over that time, such as a change from an orange to blue badge and the introduction in September 2006 of the power for police and parking enforcement officers to inspect Blue Badges, there have been very few changes to the way people are assessed and how people found mis-using badges are treated.

In my opinion these two

**I understand the reason behind consulting but when you think that the first review was in 1999, why are we still being consulted on changes over ten years later?**

issues, along with the delays, are the biggest problem with the scheme.

My concerns are shared by Joe Hennessy, Chair of the Joint Committee on Mobility for Disabled People, who speaks here in a private capacity.

"It seems like governments have been either reviewing or consulting about the Orange/Blue Badge scheme for the last 27 years, most of the time like Nero, fiddling while Rome burns.

"Both Conservative and Labour administrations have lacked the guts to sort out the mess that they and the local authorities have created. The present 'reform' programme, which is a pale imitation of what it should be, still, unbelievably, has another three-and-a-half years (make that at least



five in reality) before it is implemented. It needs to be taken from the politicians and bureaucrats and given instead to the disability organisations to rescue."

What concerns me most is that the review in 1999 came about after pressure from a number of disability organisations, including the Disabled Persons' Transport Advisory Committee (DPTAC), because of concerns at the increase in the number of badges on issue and the perceived abuse of the scheme: the same problems the scheme

**Hopefully, very soon, we will see some major improvements in the way the scheme is administered and enforced, and as a result disabled people will be able to do what the scheme intended - park!**

is experiencing today!

After the review, DPTAC made 47 recommendations

only a few of which were implemented by the Government. Maybe if more of them had been implemented at the time, the scheme wouldn't be in quite such a mess as it's in today.

The Government's reason for not implementing more of the recommendations was apparently that it needed "additional research and further cross-governmental consideration".

So now we are into yet another phase of consultation and I for one hope against hope that this will

be the last one for a very long time.

Hopefully, very soon, we will see some major improvements in the way the scheme is administered and enforced, and as a result disabled people will be able to do what the scheme intended - park!

• The consultation exercise for implementing the Blue Badge Reform Programme will run for 14 weeks, closing on 2 July 2010. If you would like to respond to the consultation, visit: [dft.gov.uk/consultations/open/2010-20](http://dft.gov.uk/consultations/open/2010-20)



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## British swimmers in world record haul

Great Britain's swimmers sent out a clear message to the rest of the world by claiming four world records at the 2010 British Gas Swimming Championships at Ponds Forge in Sheffield.

All races at the Championships took place in the multi-disability format, in which swimmers from different classifications compete in the same races. Times are then calculated against world records in each competing classification to give a points total, which determines overall placings.

Paralympic Champion Elizabeth Johnson, who competes in the SB6 category, was the first to

claim a new world mark in the 100m breaststroke final on the second day of competition.

It was European champ Claire Cashmore (SB8) who actually touched first in 1:23.26 and secured 907 points but when Beijing gold medallist Johnson touched in a new world record time for her class of 1:39.58 she took the gold medal with a total of 1,015 points.

The following day, six-time Paralympic gold medalist and eight-time World Champion Sascha Kindred (*above*) showed he is still a force to be reckoned with on the international stage as he stripped an incredible

five seconds off the previous S6 world's best in the 100m butterfly.

He touched in a time of 1:11.75 ahead of Mancunian Dave Ellis from the S13 category whose impressive swim secured a season's best time of 1:02.42.

James Hollis (S10) completed the podium places with a new personal best time of 1:06.59.

Kindred, aged 31, said his performance was the result of intense training to improve his technique.

He said: "Butterfly is something I've been working on quite a lot over the last couple of years so I'm pleased it is starting to

feel really comfortable."

Due to the multi-disability system, in the 100m backstroke, Britain's swimmers claimed two world records in the same event.

In the S7 classification, Jonathan Fox took the world record with a time of 1:11.99 earning him 1,004 points, which was also enough to claim the gold medal.

Fellow competitor James Crisp took the honours in the S9 classification with 1:03.32, scoring a total of 1,001 points. The bronze medal went to Thomas Young whose 1:08.58 earned him 905 points.



# Paralympic duo forced to quit world stage

Two British Paralympic medallists have been forced to retire from elite level competition on health grounds.

Reigning Paralympic rowing champion Helene Raynsford (*below, left*), and former World and European judo champion Ian Rose (*below, right*) have both called time on their careers.

Raynsford, 30, who was also world champion in 2006, announced her decision on the eve of the Great Britain rowing team's trials for the Paralympic boat classes.

"After my final in Beijing it was apparent something wasn't right", said Raynsford, who switched to

rowing after enjoying success as a member of the GB wheelchair basketball team.

"Post-Beijing I became increasingly unwell and unable to train fully and I was diagnosed with a cardiac problem. I've been ill in the past but always got better and didn't think for one moment I wouldn't be racing in the 2009 season or would have to retire from the sport I love.

"It has been a very difficult decision to retire. My passion for rowing, striving for excellence and drive to be part of the international rowing community is very much still there but I have to let

my body recover fully and this is something I can't do while continuing to try to train," she added.

Rose, who won a silver medal at the 2004 Paralympics in Athens and a bronze medal at the Atlanta Games in 1996 was also World Champion in 1995 and a four-time European Champion.

He was forced to rethink his plans to compete in front of a home crowd in London in 2012 after failing to recover from a persistent back injury.

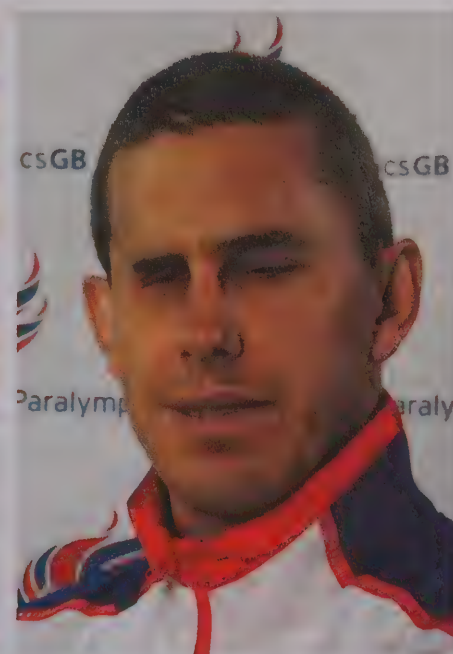
He said: "My back injuries were stopping me training to the level I need to get a medal and I didn't want to go into the competition

thinking I wasn't going to win a medal."

However, the 37-year-old will remain in the sport after being offered a position as a co-ordinator for the development scheme at the British Judo Association.

He said: "I've been in judo for 30 years. Now is the time for me to give something back to the sport that has been so good to me for so long.

"I know I have made the right decision to retire but I know equally that I will find it very hard watching the London Paralympics and seeing people there that I have beaten in the past competing for the medals," he added.





# entertainmentnow



PATRICK BALDWIN/GRAEAE

## Jenny Sealey: making access sexy

To mark the company's 30th anniversary Graeae Theatre's Artistic Director, Jenny Sealey tells *Disability Now* about her role, her enthusiasm and why she has reasons to be cheerful

**P**eople come here disempowered and disenfranchised but still fighting against barriers. I love that fire and grit. In Greek myth The Graeae were three sisters who shared an eye and a tooth. It suits us politically and emotionally: the culture of disabled people sharing resources and fighting back.

Thirty years since Nabil Shaban and Richard Tomlinson founded Graeae, their reasons are still there.

It's a space where we can explore identities and stories, profile our skills and excellence, and it's a learning ground.

There still isn't equal access to drama schools, it's getting better and we have an ever-evolving teachers' manual supporting drama schools to be inclusive, but Graeae is often the first place actors have their access needs sorted.

Disabled people auditioning have giant £

signs over our heads. Access does come at a cost but this is 2010 and it's our basic human right. We give actors' confidence to say "I have access requirements and we can get these paid for by Access to Work (ATW)".

I'm just back from a conference in Australia. It was weird talking about the freedom ATW gives me to do my job because they don't have it. An Australian opera singer lost her sight and was told she couldn't perform because she might fall off the stage. Unbelievable!

Graeae nurtures people to go out into the wider world carrying the mantle. Maybe one day there'll be so much opportunity we won't need a Graeae. We're a long way behind the Black theatre movement but we're getting there. Now Coronation Street might have two disabled characters. Why not?

Acting is about being somebody else so maybe Daniel Day Lewis as Christy Brown was bloody good, but did they give a disabled actor the opportunity to audition? If you aren't casting a disabled Richard III then have disabled actors in other roles in the play. Directors need to be more imaginative.

We're making access a sexy word! Exploring the aesthetics of access, we're

in a position to find things out creatively. How does an actor with a differing voice pattern play a snooty aristocrat in a Restoration comedy? Maybe he's too posh to speak so delegates the talking to his servant.

We layer the work: words, music, visuals tell the story.

**“In Greek myth The Graeae were three sisters who shared an eye and a tooth. It suits us politically and emotionally: the culture of disabled people sharing resources”**

It's multi-sensory. There are so many ways to communicate and collaborate. I used drawings and eye contact to design a whole show with a French designer whose English I couldn't lip read.

We've used stage directions as audio description in *The Fall of the House of Usher* and *Blasted*. And we want writers to think about access from the start. Young blind people told us they didn't want to wear headsets so in *The Diary of an Action Man* the protagonist describes his adventure through his diary.





From left to right: Amit Sharma, David Ellington and Karen Spicer in *Diary of An Action Man*, 2003

We're still battling with education models. When they say integration, I think on whose terms? Learning, I find easier in a disabled or deaf environment. There's the safety to make mistakes, plus I don't have anything to prove. I'd have benefitted from being educated with other deaf people but I wouldn't be the person I am now.

I have huge gaps in my education but I make what I do know stretch.

I have a recurring nightmare that my colleagues find me on the phone, say "You can hear!" and I lose my job. I went deaf when I was seven so it absolutely defines who I am but I'm still learning how to be deaf. Learning BSL felt like coming home. We have

to make sure that young disabled people get the chance to be the disabled people they want to be and 2012 is a huge opportunity. Art challenges ideas of what disabled people can do and so does Paralympic sport.

Unlimited [the Cultural Olympiad programme] will be a beautiful programme of work and a stamping

ground for new and emerging artists. We have to leave an extraordinary legacy because we don't want the younger generation still scraping at glass ceilings. 2012 is the time to smash them and it's only two years away.

Our first Unlimited funded work is *Garden*, a sway pole piece at the Greenwich festival this June and in September look out for *Reasons to be Cheerful*, a musical based on the songs of our late patron Ian Dury, and we're fundraising for a disabled writers' group.

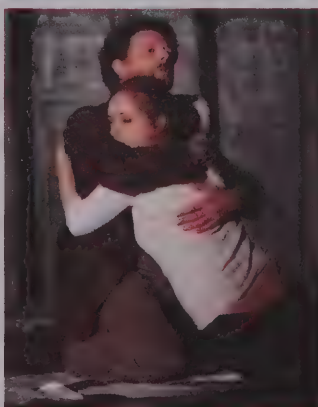
It's my ambition to create something 100 per cent accessible. It's never going to happen but by God am I going to try! That's the artistic ambition of Graeae. Never ever can we sit on our laurels. There's always a new way of doing something. There's so much to learn, so much to do, I want to do it all.

## THEATRE

### POLAR BEARS

*Polar Bears* is a debut play by Mark Haddon, author of the bestselling novel *The Curious Incident of the Dog in the Night-time*. It's an ensemble piece about the family dynamics around Kay, a woman with bipolar disorder.

Can a writer without bipolar disorder legitimately



DONMAR WAREHOUSE

write about it without being accused of tourism? In this case the tourist's snapshot is a family portrait. Most narratives about manic depression are biographical and they aren't about ordinary people but focus on the chaotic creative lives of legends such as Spike Milligan, Vincent Van Gogh or Virginia Woolf. These

stories foreground the manic maverick: the significant others servicing the great genius pop up in bit parts but as Andy Rickell says elsewhere in this issue, human life is about interdependency.

In *Polar Bears* we get to see how very different characters interact with Kay. And she might not even be →



a creative genius! Well at times she reckons she is, but contradictory scenes leave room for doubt.

In fact everything that happens in *Polar Bears* leaves room for doubt. Has Kay been killed by her husband's kindness, her putrefying body stashed in the cellar, or is she in Oslo promoting her award-winning illustrated children's book?

These contradictory scenes make unreliable narrators of all the cast. Someone is deluded but is it Kay, or her loving but resentful

husband, or her cynical brother, or her mother who needs her as a project to work on? This seems like a clever way of putting the audience in the shoes of a person doubting their own perception of reality.

Other contrivances are less smooth. It might be a handy rhetorical device for Kay's husband John to be an academic philosopher but at times it seems like an excuse to shoehorn in a load of research on Nietzsche.

Having bipolar disorder "in the family" means that it's not just the mental

health of the people carrying the gene that are affected. *Polar Bears* touches on the taboo of "carers" wishing death to the troublesome disabled loved one but might go too far in almost justifying domestic violence.

Initially I was dubious about the old pun in the title but with extremes of give and take, loving a person with bipolar disorder

can be tricky, making the identification with an animal that kills by hugging seem fitting.

Perhaps the observant visitor can pick up on things we natives miss and it's sometimes interesting to see how others see us and our differently mental but undiagnosed families.

**Kelly Mullan**

• Donmar Warehouse until 22 May

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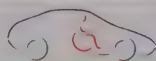
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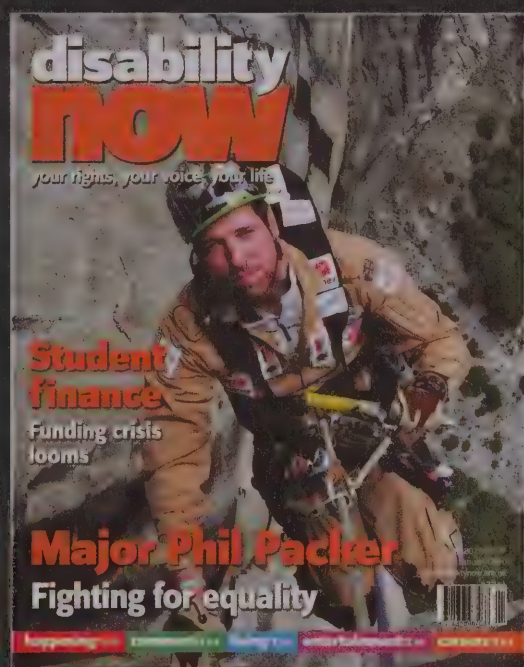
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# webwatch

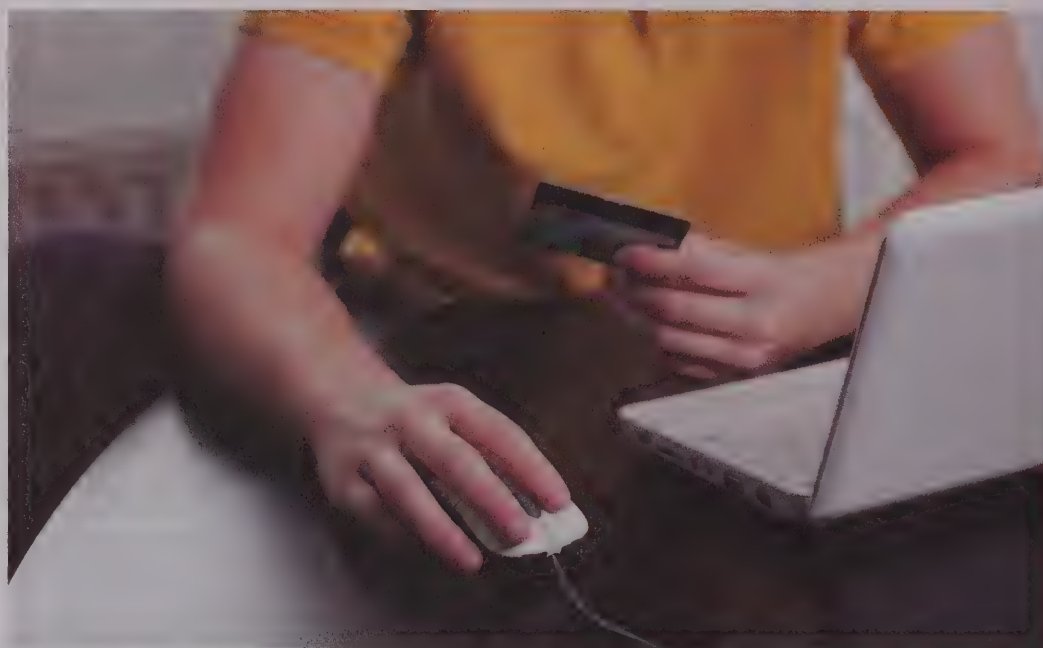
**A**s some people have pointed out, the virtual world can be a lot more accessible than the real world!

For example, just think about shopping. More and more of us are doing it online these days. Despite the “credit crunch”, internet shopping in Britain is booming, and over 20 million British people now shop online according to market researchers.

The popularity of online shopping is based on its convenience. For disabled people, online retailing can also help to overcome accessibility problems, communication barriers and transport issues.

Another benefit is clearly the much greater ease with which we can exchange information over the internet, potentially (if not actually) in a variety of accessible formats, large print, audio, easy read and so on. This easy communication is a major boon to self-help, campaigning and support groups of all kinds.

Disabled people are among the most enthusiastic users of social networking. Sites such as Facebook offer a large number of disability related interest groups, and they also offer the opportunity to make your disability “invisible” if preferred. On the downside, those using social



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## Off the pace in the virtual race

With politicians of all hues committed to expanding broadband and bringing the internet to everyone, market researcher and disabled web user **Graham Kelly** ponders the reality of access and economic barriers between disabled people and the world of the web

networking should be aware that, as Tom Shakespeare has said, such sites “provide a forum which bored idiots can fill with prejudice and filth”.

So, that all sounds great, but disabled people are in fact much less likely than the rest of the population to use the internet.

The Office for Disability Issues report “*Experiences and Expectations of Disabled People*” found that, in 2007, only 42 per cent of disabled people had home internet access, compared to 65 per cent of the general

population. Both of these figures will have risen in the last two years, but there is no reason to think that the gap has closed. Indeed data from

**Disabled people are in fact much less likely than the rest of the population to use the internet**

Ofcom for 2009 suggests that the gap may be widening, with internet access among the general population increasing strongly to 73 per cent, but

increasing more slowly among those with visual impairments, and not increasing at all among those with mobility and hearing impairments. If this trend is confirmed by the more robust data being gathered by the Office for National Statistics, it will make a mockery of the Government’s aim to “narrow the digital divide”.

There are a number of reasons why disabled people’s use of the internet is relatively low. These include physical accessibility



barriers (e.g. sensory or dexterity related) and poor website design, but the major reasons lie elsewhere.

Firstly, we know that older people are less likely than younger people to use the internet, and the disabled population has an older profile than the general population. Secondly, we know that the highest levels of internet usage are found amongst more affluent social groups, but the disabled population tends to be more disadvantaged, with lower incomes. Thirdly, some disabled people have

specific barriers to internet usage, particularly around cost, confidence, knowledge and worries about data security/viruses.

Clearly many disabled people are missing out on the opportunities that the internet could bring, but more worryingly commercial suppliers are increasingly making products and services available only via online channels. Indeed, government is also attracted to the idea of dealing with the public online, because providing customer services over the internet is much

cheaper than doing so face-to-face, or even through call centres. We may see a trend towards faster, more efficient public services delivered online, whilst off-line citizens rely on "special services", which become overstretched and under-resourced, in an era in which reducing costs is the priority of public services.

Undoubtedly the disabled

community should "watch this space" very closely over the next few years.

Specifically, the danger to look out for is that whilst the internet enhances the lives of the many, some significant groups of disabled people may find that it reinforces their social exclusion.

• Graham Kelly is Director of the social research company Word of Mouth

### → Have your say

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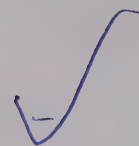
For more information contact Sue Jenkins, Cerebral Palsy Plus, 1 0117 965 5028 or [office@cerebralpalsyplus.org.uk](mailto:office@cerebralpalsyplus.org.uk)

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# Nova-Caine eases Jacqueline's pain

Not being able to get out of bed only made **Jacqueline May** more determined to have the career of her dreams. Now a fully-fledged band manager, events organiser and music promoter, Jacqueline has learnt how to both work and play from the comfort of her sitting room

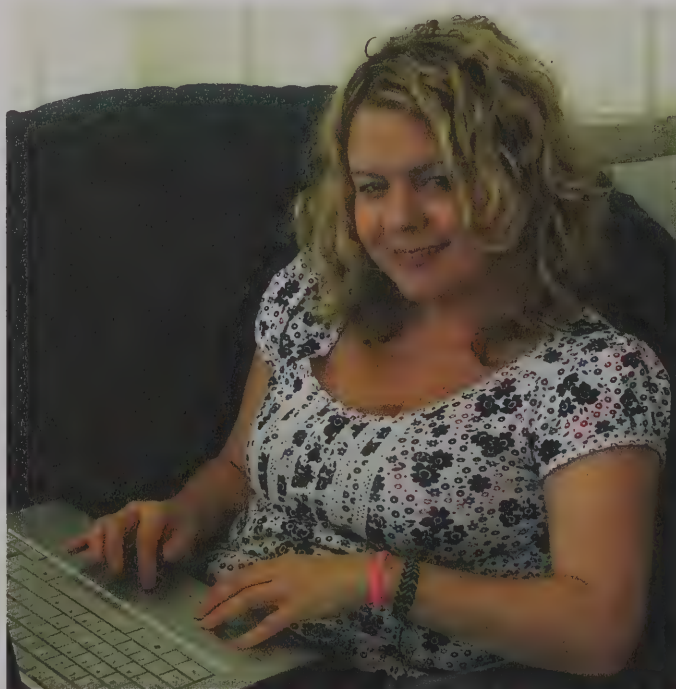
**W**hen I was three years old my mother took me to the doctors because I kept crying in agony for no apparent reason. My GP said I was attention-seeking; it wasn't until just before my eighth birthday that I was diagnosed with arthritis.

Because of this, even though I have attempted to work all my life, I have only managed to hold down jobs for between three and six months at a time.

When I was a teenager my friends used to pick me up in their cars and take me to concerts. I've always dreamed of having a job in the music industry, and now I do.

I moved to London and started working for a mail order company that dealt with really rare music, but I found that I physically couldn't stay there. I went for yet another hip replacement and realised that I wouldn't be able to continue working in offices, it just wasn't practical.

I was sitting at home, depressed, when a friend in an up-and-coming band approached me and said



"help me out if you want something to do during the day, help me try and get us gigs, some airplay".

A couple of months ago, his group, Razorbax finished their first album. They picked a release date and I got to work. My boyfriend is an IT whizz and built me a website through which I sell their music and promote them. I've found social networking brilliant too; the band is fantastic, their product sells itself, you just have to let people know about it. In the last few weeks they've gained

hundreds of friends and fans online and I've had calls from all over the world, wanting to know more, wanting to hear them or see them play.

More artists have heard about the work I'm doing and asked for my help,

which is great. In this job I can afford to pace myself. I can't predict how I'm going to feel. I get tired very easily so I'll stop between emails and have a rest.

I've been very open about my condition and everyone is completely accepting of it. I do what I can do and at the point where I can't do anymore I ask for help. It doesn't pay the bills yet, but eventually I do want to be able to have a career where I don't have to keep an eye on the benefits system. I want to be self-sufficient.

I'm doing this to build a reputation, for the love of the music and because I know it will give me a future. And it's really exciting.

• To find out more about Jacqueline or Razorbax visit [nova-caine.com](http://nova-caine.com)  
• • Jacqueline May was talking to Cathy Reay

## JACQUELINE MAY: CAREER PATH

- 2000 – graduated with a degree in film and TV production
- 2000 – worked in Ticketmaster's call centre as a customer service representative
- 2004 – got a job at a marketing company
- 2007 – worked for a music mail order company in London
- 2008 – quit work and moved north due to illness
- 2009 – met Razorbax and set up Nova-Caine Music



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### PERSONAL

**MALE WITH LEG** injury. 60 years old. Seeking partner. My interests include travel & dining out. Car driver. Kent & South London area. Email: **daveychef@yahoo.co.uk** or Box no: A2

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2007(07)	Renault Kangoo 1.6 Expression Auto, A/C, 27,000 mls	£10,795
2007(07)	Peugeot Partner 1.4 Totem, A/C, 5 sp, 2,000 mls	£10,795
2009(58)	Renault Kangoo 1.6 Authentique auto, 7,000 mls	£10,795
2007(57)	Renault Kangoo 1.6 Authentique auto, A/C, 22,000 mls	£10,995
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2007(07)	Kia Sedona CRDi LS, 5sp, A/C, Full Low Floor, 6,000 mls	£18,995
2008(08)	Vauxhall Zafira 1.8 Club, 5sp, A/C, Full Low Floor, 5,000 mls	£18,995
2010(10)	Kia Sedona CRDi GS, A/C, Full Low Floor, 300 mls	£22,995
2010(10)	Ford Galaxy 1.8 Dci Edge, 5sp, A/C, Low Floor, 5 seats, NEW	£24,395
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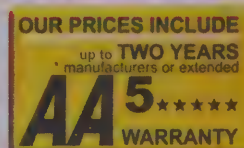
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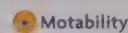
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# backlash



## Carter's culinary clutter

Gadget-boy **Paul Carter** faces up to the realisation that it's time to put aside all those things which perpetuate the pretence that he's any kind of kitchen wiz

I've decided that I'm now officially getting old. I came to this rather depressing conclusion when I caught sight of myself trying to decide which brand of food processor I'd like to buy for my kitchen. After all, nothing says you're no longer a young person than thinking "ooh I really fancy making some pâté".

I decided against buying one in the end though. Partly because I would have had to trade the rest of an aggregate arm and a leg to pay for one, but mainly due to the fact that after a few days of novelty use, it would almost certainly find itself eventually consigned to the same fate as all the other kitchen objects I've purchased over the years in the vain attempt to make cooking more accessible. Namely the back of the top cupboard I can't reach into without a step ladder.

Over the years I've acquired electric pans, mini choppers, weird rubber things to put jars in to open, handles to pop the lids of jars with and all other assortment of weird and wonderful paraphernalia. The only one I actually get any



**“I have so many ridiculous cooking gadgets now that my kitchen looks like some sort of culinary Batcave”**

regular use out of these days is my trusty egg cracker.

I have so many ridiculous cooking gadgets now that my kitchen looks like some sort of culinary Batcave. If (heaven forbid) I actually decide to try and make something that requires following an actual recipe, working out what equipment to use, in what order, is such a complicated

process that I half expect some sort of Q character to pop out from under the sink to give me a technological briefing.

I'm not really sure why I bother though to be honest. After all, if you look hard enough, you can buy most stuff from supermarkets these days that is so pre-prepared it practically slaughters, bastes and cooks itself.

Last time out I spied sliced mushrooms, diced chicken, chopped onions – even pre-mashed potatoes. I swear I'm not making any of these up either. Admittedly most of these products are

probably made for spectacularly lazy people with children named Tarquin or Hector as opposed to indifferent, finger deficient, lazy oiks like me, but still. They do a job.

I should probably just come to accept the fact that I'm not cut out for proper adult cooking. After all, life's too short to be peeling ginger. In true *Come Dine With Me* fashion, I'm supposed to be hosting a dinner party at the end of the month. I hope my guests like pizza. Don't worry about the effort involved though, I have Domino's on speed dial.



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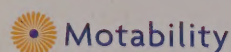
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